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## Physician-Assisted Suicide and Dementia: The Impossibility of a Workable Regulatory Regime

Creating a physician-assisted suicide (PAS) regime for cancer, ALS,<sup>1</sup> and AIDS is relatively easy. While to be human is to be a “being-unto-death,”<sup>2</sup> meant to suffer from the terminal malady of mortality, as a community we are comfortable with the notion that a distinct meaning adheres to the category of “terminal illness.”<sup>3</sup> And

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<sup>1</sup> “Amyotrophic lateral sclerosis (ALS) is a progressive, adult-onset motor neuron disease characterized by loss of motor function and ultimately death.” KATHRYN BAYLES & CHERYL TOMOEDA, *COGNITIVE-COMMUNICATION DISORDERS OF DEMENTIA* 130 (2007).

<sup>2</sup> See Michael Bavidge, *Ageing and Human Nature*, in *DEMENTIA: MIND, MEANING, AND THE PERSON* 41, 50 (Julian C. Hughes et al. eds., 2006) [hereinafter *DEMENTIA*]. The characterization of man as a “being unto death” initially comes from the philosopher Heidegger. See generally MARTIN HEIDEGGER, *BEING AND TIME* (1980).

<sup>3</sup> See Howard Brody, *Assisted Suicide for Those Not Terminally Ill*, *HASTINGS CENTER REP.*, Jan.–Feb. 2001, at 7, 7 (“The factual point is a reminder that the term ‘terminal’ has very limited medical utility and significance.”).

For example, under the Oregon Death with Dignity Act it is unclear whether the definition of terminal is meant to be with or without treatment. JOHN KEOWN, *EUTHANASIA, ETHICS AND PUBLIC POLICY: AN ARGUMENT AGAINST LEGISLATION* 167, 171 (2002); see also Daniel Callahan & Margot White, *The Legalization of Physician-Assisted Suicide: Creating a Regulatory Potemkin Village*, 30 U. RICH. L. REV. 1, 44–45 (1996). Further, over fifty percent of Oregon doctors say they cannot predict whether a patient will die within six months. See KEOWN, *supra*, at 172. But see Yale Kamisar, *The*

while physicians may lack confidence in their abilities to predict when one with such an illness has less than six months to live<sup>4</sup> (as is the accepted timeline in current and proposed PAS statutes<sup>5</sup>), this does not bother society. Their prediction will be close enough for government work literally as hospice care is available under Medicare only when one has ceased all curative therapy and has been diagnosed with less than six months to live.<sup>6</sup> Maybe the patient will live longer, maybe less. But barring a rare miracle, they are going to die soon. Leave them alone. The diagnosis of “six months to live,” while if pushed analytically may be revealed as a metaphor rather than a literal chronological measure of time, nonetheless presents to the world an appearance of a noninterpretive bright line: six months is six months, June to December.

Interestingly, neither of the two primary metaphors weaving in and out of the current PAS dialogue—“death with dignity”<sup>7</sup> and “unbearable suffering”<sup>8</sup>—correlate strongly with six months to live.

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“*Right to Die*”: *On Drawing (and Erasing) Lines*, 35 DUQ. L. REV. 481, 504 (1996) (“Deciding what should count as terminally ill will pose such severe difficulties that it seems untenable as a criterion for permitting physician-assisted suicide.” (internal quotation marks omitted)).

<sup>4</sup> See KEOWN, *supra* note 3, at 172.

<sup>5</sup> For example, the Oregon Death with Dignity Act and the equivalent, recently passed Washington statute require that the patient be “diagnosed with a terminal illness that will lead to death within [six] months.” JOHN B. MITCHELL, UNDERSTANDING ASSISTED SUICIDE: NINE ISSUES TO CONSIDER 90 (2007); see Janet I. Tu, *Assisted Suicide Measure Passes: Initiative 1000*, SEATTLE TIMES, Nov. 5, 2008, at A3. Likewise, the failed California Compassionate Choices Act required an “incurable and irreversible disease” that would “within reasonable medical judgment, produce death within six months.” A.B. 374, 2007–2008 Leg., Reg. Sess. (Cal. 2007).

<sup>6</sup> See 42 C.F.R. § 418.20 (2009) (providing eligibility requirements for hospice care under Medicare); 42 C.F.R. § 418.22 (b)(1) (“The certification must specify that the individual’s prognosis is for a life expectancy of [six] months or less if the terminal illness runs its normal course.”).

<sup>7</sup> This right is alleged to sound in autonomy. John B. Mitchell, *My Father, John Locke, and Assisted Suicide: The Real Constitutional Right*, 3 IND. HEALTH L. REV. 43, 57 (2006). The right has alternatively been described as the “right to die,” ALAN MEISEL, THE RIGHT TO DIE 3–12 (1989), the right to “choose and to control the time, place, conditions, and manner of dying,” MARGARET SOMERVILLE, DEATH TALK: THE CASE AGAINST EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE 31 (2001), and “death with dignity,” Callahan & White, *supra* note 3, at 20; Martin Gunderson & David J. Mayo, *Altruism and Physician Assisted Death*, 18 J. MED. & PHIL. 281, 284–87 (1993); see also Mitchell, *supra*, at 57–60 (surveying the various notions of “dignity”).

<sup>8</sup> Unlike the Oregon statute, see generally MITCHELL, *supra* note 5, the Netherlands based access to assisted death (or “euthanasia,” as they refer to it) on the concept of “unbearable suffering.” See KEOWN, *supra* note 3, at 108–10; ROBERT I. MISBIN, EUTHANASIA: THE GOOD OF THE PATIENT, THE GOOD OF SOCIETY 69, 72–73 (1992).

“Death with dignity” is, as the phrase states, about the manner of one’s death. People react to the narrative—tubes, soiled adult diapers,<sup>9</sup> complete dependence<sup>10</sup>—and become upset beyond comprehension. But nothing in that story correlates with “terminal illness” conjoined with “six months to live.” The metaphor of “unbearable suffering,” in contrast, is a function of living. While the public discourse about unbearable suffering rests primarily upon images of rampaging physical pain,<sup>11</sup> “suffering” is far more complex

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Problematically for those seeking to confine the scope of PAS under an unbearable suffering standard is that suffering encompasses far more than physical pain. See E. Emanuel et al., *Evaluating Requests for Assisted Suicide*, in EUTHANASIA: CONTEMPORARY ISSUES COMPANION 49, 50–51 (Lisa Yount ed., 2002) (“Loss of control, fear of abandonment or burdening others, financial hardships, physical and psychological symptoms, and personal beliefs are all potential causes of suffering.”). See generally DANIEL CALLAHAN, *THE TROUBLED DREAM OF LIFE: IN SEARCH OF A PEACEFUL DEATH* 100–02 (2000); Nathan I. Cherny & Russell K. Portenoy, *Sedation in the Management of Refractory Symptoms: Guidelines for Evaluation and Treatment*, 10 J. PALLIATIVE CARE 31, 34 (1994) (“The approach suggested in the evaluation of unrelieved physical symptoms becomes more difficult if symptoms are psychological or suffering is perceived to relate to existential or spiritual concerns.”); Harvey M. Chochinov & Leonard Schwartz, *Depression and the Will to Live in the Psychological Landscape of Terminally Ill Patients*, in THE CASE AGAINST ASSISTED SUICIDE: FOR THE RIGHT TO END-OF-LIFE CARE 261, 298–302 (Kathleen Foley & Herbert Hendin eds., 2002) [hereinafter THE CASE AGAINST ASSISTED SUICIDE]; Stacy DiLoreto, *The Complexities of Assisted Suicide*, 34 PATIENT CARE 65, 69 (2000); Herbert Hendin, *Suicide, Assisted Suicide, and Medical Illness*, HARV. MENTAL HEALTH LETTER, Jan. 2000, at 4–7; Zbigniew Zylicz, *Ethical Considerations in the Treatment of Pain in a Hospice Environment*, 41 PATIENT EDUC. & COUNSELING 47, 47–53 (2000). In fact, the Dutch have approved euthanasia for extreme psychological suffering. See MITCHELL, *supra* note 5, at 83.

<sup>9</sup> See Mitchell, *supra* note 7, at 60.

It is this latter narrative, this *dying without dignity*, which the proponents of PAS sought to prevent. In this bad death narrative, the person is in pain and soiling himself, with tubes and machines humming away . . . Why must a patient endure this? Why can the patient not exercise his autonomy and choose to end this mockery of his existence with the assistance of a physician through PAS? To permit less denies them the right to die with dignity.

*Id.* (footnote omitted).

<sup>10</sup> See DANIEL GILBERT, *STUMBLING ON HAPPINESS* 22 (2006).

The fact is that human beings come into the world with a passion for control, they go out of the world the same way, and research suggests that if they lose their ability to control things at any point between their entrance and their exit, they become unhappy, helpless, hopeless, and depressed. . . . And occasionally dead.

*Id.* (footnote omitted).

<sup>11</sup> See, e.g., DEREK HUMPHRY & MARY CLEMENT, *FREEDOM TO DIE: PEOPLE, POLITICS, AND THE RIGHT-TO-DIE MOVEMENT* 57 (1998); Paul van der Maas & Linda L. Emanuel, *Factual Findings*, in REGULATING HOW WE DIE: THE ETHICAL, MEDICAL, AND

than physical pain, including the psychological, emotional and existential aspects within its ambit.<sup>12</sup> Again, a person with a terminal illness and six months to live may suffer great pain, and some certainly do, but not invariably so.

So, what is going on? Acceptance of PAS reflects intuitions about the entitlement of autonomous individuals to try to influence some of the details of the otherwise inevitable. The attitude is: "I know I'm going to go, but I'd like to go in my own small way if I can."<sup>13</sup> Still, those intuitions cannot be wholesale inserted into the concrete reality of social life without concern about cabinining their scope. In short, counterintuitions tell us that we do not want to sanction at-will PAS. So our choice is "terminal" plus "six months." This limitation neatly circumscribes the scope of PAS under circumstances that serve as a comfortable proxy for the death with dignity and unbearable suffering metaphors. As I previously mentioned, cancer, ALS, and AIDS are easy; dementia is not.

The debate over PAS will face the greatest complexities and challenges concerning PAS and dementia.<sup>14</sup> As shall be shown,

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LEGAL ISSUES SURROUNDING PHYSICIAN-ASSISTED SUICIDE 151, 157 (Linda L. Emanuel ed., 1998) (stating that "less than [ten] percent of cancer cases involve untreatable pain").

<sup>12</sup> See *supra* note 8.

<sup>13</sup> See Mitchell, *supra* note 7, at 61.

<sup>14</sup> Dementia will not be the only contender for expanding the scope of PAS beyond the "terminal, six months to live" framework. On a conceptual level, the question has been raised whether respect for autonomy and the desire to end suffering—the moral values allegedly underlying PAS—can be confined to terminal illnesses. *Id.*

To suggest that all competent adults have the right to physician assisted suicide would be startling to most. The fact is that over time, it may be difficult to limit PAS's use to those we now envision as terminally ill and suffering. First, assuming we can even define who is and who is not terminally ill, . . . it will not be reasonable to confine the right to only the terminally ill. . . . Non-terminal patients suffering as the result of massive injuries or those inflicted with a wasting disease can, in some ways, be in a far worse position than those with a terminal illness, e.g. six months or a year to live. The suffering of non-terminal patients can go on and on, while, for the terminally ill, the end is in sight.

*Id.* (footnotes omitted). Wasting diseases, such as Parkinson's, and severe disabilities will likely also be raised as candidates for PAS. Of note, former Governor Booth Gardner, who is suffering from Parkinson's disease, led a successful campaign in Washington State for an Oregon-like PAS law. See Daniel Bergner, *Death in the Family*, N.Y. TIMES, Dec. 2, 2007, § 6 (Magazine), at 38, 40. In fact, the majority of those seeking the assistance of Dr. Jack Kevorkian had degenerate, rather than terminal, illnesses. See Brody, *supra* note 3, at 7. The challenge will be to establish a method for deciding *when* such a person may be entitled to PAS. The time from first diagnosis to substantial physical degenerations may be many years. What metaphor should be chosen to give sufficient clarity to when the line justifying access to PAS has been crossed? Physical disabilities bear significant issues in addition to the need to develop an acceptable metaphor to describe the physical

dementia is not capable of neat definitions or bright lines comparable to “six months to live.” “No hard scientific boundary [separates] disease [dementia] and [normal aging].”<sup>15</sup> Instead, dementia is a syndrome<sup>16</sup> during which a person suffers from “multiple cognitive deficits sufficient to interfere with social and occupational functioning.”<sup>17</sup> Yet there can be no doubt that dementia is accompanied by at least as strong an image of “loss of human dignity” and “suffering” as accompanies cancer. I have some personal sense of this. My mother had dementia. She lived in an Alzheimer’s residence, and died from Alzheimer’s disease.

In considering PAS and dementia, one faces issues of significant scale, both numerical and conceptual. Numerically, four-and-a-half

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condition qualifying the individual as a candidate for PAS. The disability community has consistently expressed apprehension concerning the legalization of PAS. For example, “a long list of state and national disability rights organization [sic]” joined other constituencies in opposing California’s proposed PAS law. See *Californians Against Assisted Suicide: For the Third Time in Three Years, Assisted Suicide Fails to Get Support in the Assembly*, BIOTECH WEEK, June 27, 2007, at 976. See generally Timothy H. Lillie & James L. Werth, Jr., *End-of-Life Issues and Persons with Disabilities: Introduction to the Special Issue*, 16 J. DISABILITY POL’Y STUD. 2 (2005). Underlying the disability community’s opposition are two concerns. First, PAS currently would take place within a societal context where the lives of the disabled are perceived to be worth less than the lives of the nondisabled (a so-called “ablest society”). See, e.g., Ron Amundson & Gayle Taira, *Our Lives and Ideologies: The Effect of Life Experience on the Perceived Morality of the Policy of Physician-Assisted Suicide*, 16 J. DISABILITY POL’Y STUD. 53, 55 (2005) (stating that some caregivers believe the seriously disabled would be “better off dead”); Rhoda Olkin, *Why I Changed My Mind About Physician-Assisted Suicide: How Stanford University Made a Radical Out of Me*, 16 J. DISABILITY POL’Y STUD. 68, 70 (2005) (stating that “people without disabilities judge the quality of the lives of people with disabilities more harshly than do the people with disabilities themselves”); James L. Werth, Jr., *Concerns About Decisions Related to Withholding/Withdrawing Life-Sustaining Treatment and Futility for Persons with Disabilities*, 16 J. DISABILITY POL’Y STUD. 31, 32 (2005) (noting that people with disabilities are often considered to have a poor quality of life).

Second, that same ablest society continues to deny the disabled the support and material resources needed in order to live a life fulfilled. See Paul K. Longmore, *Policy, Prejudice, and Reality: Two Case Studies of Physician-Assisted Suicide*, 16 J. DISABILITY POL’Y STUD. 38, 38–44 (2005) (showing how discrimination regarding access to services led quadriplegics to seek PAS); Richard Radtke, *A Case Against Physician-Assisted Suicide*, 16 J. DISABILITY POL’Y STUD. 58, 58 (2005) (observing that an “unsupportive environment” can cause the disabled to underestimate the potential for a decent quality of life).

Without massive efforts to educate the public about the disabled, along with corresponding changes in public attitudes and increased provisions for needed material resources, this strong opposition will likely continue.

<sup>15</sup> Julian C. Hughes et al., *Seeing Whole*, in *DEMENTIA*, *supra* note 2, at 1, 2.

<sup>16</sup> See BAYLES & TOMOEDA, *supra* note 1, at 3.

<sup>17</sup> *Id.*

million Americans currently suffer from Alzheimer's disease,<sup>18</sup> the leading cause of dementia in older adults.<sup>19</sup> By the middle of the century (unless a cure is found<sup>20</sup>) as many as fourteen million adults may suffer from Alzheimer's disease.<sup>21</sup> In comparison, 10.8 million people in this country had some form of cancer in 2004.<sup>22</sup> Alzheimer's, moreover, causes only a little over half of all dementia.<sup>23</sup> Vascular (i.e., strokes) dementia,<sup>24</sup> Lewy body dementia,<sup>25</sup> Pick's disease,<sup>26</sup> other rarer causes,<sup>27</sup> and so-called

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<sup>18</sup> LYNDA A. MARKUT & ANATOLE CRANE, *DEMENTIA CAREGIVERS SHARE THEIR STORIES: A SUPPORT GROUP IN A BOOK* 3 (2005); *see also* RONALD DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM* 189 (1993) (stating that one quarter to one half of those over eighty-five are seriously demented); NANCY L. MACE & PETER V. RABINS, *THE 36-HOUR DAY: A FAMILY GUIDE TO CARING FOR PERSONS WITH ALZHEIMER DISEASE, RELATED DEMENTING ILLNESSES, AND MEMORY LOSS IN LATER LIFE* 7 (3d ed. 1999) (stating that there are an estimated "[four] million people in the United States [that] have some degree of intellectual impairment"); Alison Phinney, *Living with Dementia from the Patient's Perspective*, J. GERONTOLOGICAL NURSING, June 1998, at 8, 9 (estimating that eight percent of individuals sixty-five and older in North America, Europe, and Asia have dementia). Those over eighty-five comprise the fastest growing segment of our population. *See* DEREK HUMPREY & MARY CLEMENT, *FREEDOM TO DIE: PEOPLE, POLICIES, AND THE RIGHT TO DIE MOVEMENT* 9–10 (2000).

<sup>19</sup> *See* BAYLES & TOMOEDA, *supra* note 1, at 2. Note, however, that the only way to diagnose Alzheimer's disease with certainty is through an autopsy. *See* MACE & RABINS, *supra* note 18, at 293.

<sup>20</sup> *See* MACE & RABINS, *supra* note 18, at 298–311 (describing current research); Carmelo Aquilina & Julian C. Hughes, *The Return of the Living Dead: Agency Lost and Found?*, in *DEMENTIA*, *supra* note 2, at 143, 148–49; *see also* Roger Bullock, *New Drugs for Alzheimer's Disease and Other Dementias*, 180 *BRIT. J. PSYCHIATRY* 135, 135–39 (2002).

<sup>21</sup> *See* BAYLES & TOMOEDA, *supra* note 1, at 2; Stephen G. Post, *Severely Demented Elderly People: A Case Against Senicide*, 38 *J. AM. GERIATRIC SOC'Y* 715, 715 (1990). In fact, these numbers may understate the truth. A recent Mayo Clinic study indicates that an additional one million older Americans suffer a "milder type of mental decline that often precedes Alzheimer's." *See* Marilyn Marchione, *U.S. Facing "Crisis" of Millions with Pre-Dementia*, *SEATTLE POST-INTELLIGENCER*, July 29, 2008, at A5.

<sup>22</sup> *See* AM. CANCER SOC'Y, *CANCER FACTS & FIGURES 2008*, at 1 (2008), available at <http://www.cancer.org/downloads/STT/2008CAFFfinalsecured.pdf>.

<sup>23</sup> *See* BAYLES & TOMOEDA, *supra* note 1, at 2; MARKUT & CRANE, *supra* note 18, at 1; MACE & RABINS, *supra* note 18, at 290 (discussing that Alzheimer's comprises fifty to sixty percent of dementia cases).

<sup>24</sup> *See* BAYLES & TOMOEDA, *supra* note 1, at 2, 83.

<sup>25</sup> *Id.* at 2, 105.

<sup>26</sup> For a description of this rare brain disorder, *see* MARKUT & CRANE, *supra* note 18, at 4.

<sup>27</sup> Dementia can also be the result of Down syndrome, BAYLES & TOMOEDA, *supra* note 1, at 75–76; Parkinson's disease, *id.* at 93; Huntington's disease, *id.* at 115;

“mixed” dementias<sup>28</sup> (e.g., vascular disease and Alzheimer’s disease combined) will only add to the number of adults with dementia.

The conceptual aspects of PAS and dementia will likewise play out on a large scale. The dialogue over assisted suicide for the terminally ill currently revolves around notions such as dignity, sacredness of life, autonomy, and slippery slopes. While such concepts will retain a place in any consideration of PAS for the demented, they will not reside at the center. Rather, at the core of this dialogue will be competing, complex narratives—constructed from cultural lore, philosophy, and medicine—over the extent to which the demented are full human beings, entitled to be valued as such. For the more those suffering dementia are placed in narratives where they are “no longer the same person,” or lacking “the prerequisites of being human,” or mere “empty shells,” the easier for the tremendous individual, familial,<sup>29</sup> and societal burdens<sup>30</sup> of dementia to outweigh the

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frontotemporal dementia, *id.* at 123–24; ALS, *id.* at 130; or AIDS, MACE & RABINS, *supra* note 18, at 294–95.

<sup>28</sup> See BAYLES & TOMOEDA, *supra* note 1, at 2.

<sup>29</sup> If the family members act as the caregivers, the toll on them is often overwhelming. See MARKUT & CRANE, *supra* note 18, at 118 (discussing the importance of support groups for family members functioning as caregivers); Lisa Brodoff, *Planning for Alzheimer’s Disease with Mental Health Advance Directives*, 17 ELDER L.J. 239, 240 (2010). The literature is filled with descriptions of the stress on caregivers. MARKUT & CRANE, *supra* note 18, at 160; see also BAYLES & TOMOEDA, *supra* note 1, at 219–24; MACE & RABINS, *supra* note 18, at 235–36. Intertwined with emotional stress are the huge economic pressures accompanying the care of the demented.

Total healthcare costs are more than three times higher for people with Alzheimer’s and other dementias than for other people age 65 and older . . . .

. . . .

People with Alzheimer’s are high consumers of hospital, nursing home and other health and long-term care services, which translates into high costs for Medicare, Medicaid and millions of families. As families struggle to survive in a deepening recession and as states grapple with budget shortfalls, Alzheimer’s disease threatens to overwhelm them both. . . .

. . . In addition to the unpaid care families contribute, the report also reveals that Alzheimer’s creates high out-of-pocket health and long-term care expenses for families.

Press Release, Alzheimer’s Ass’n, New Report Says Alzheimer’s Disease and Dementia Triple Healthcare Costs for Americans Age 65 and Older (Mar. 24, 2009), *available at* [http://www.alz.org/national/documents/release\\_032409\\_factsfigures.pdf](http://www.alz.org/national/documents/release_032409_factsfigures.pdf).

<sup>30</sup> The current yearly cost to society of dementia is estimated to be one hundred billion dollars. BAYLES & TOMOEDA, *supra* note 1, at 3. For a discussion of the nature and scope of the current stress on the health care system, see generally BILL BYTHEWAY, AGEISM 52–55 (1995) (describing the presence of panic in a culture that the elderly will use up health care resources); SOMERVILLE, *supra* note 7, at 13; PAUL STARR, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE: THE RISE OF A SOVEREIGN PROFESSION

concern for the fate of the demented person. On the other hand, narratives positioning the demented as persons who, while perhaps diminished, remain fully human make it difficult to relegate this group to the realm of instrumental, cost-benefit analysis.

Attaining the latter situation is vital. Put simply, it is impossible to create a workable, legal regulatory regime regarding PAS and dementia. Due to a fundamental paradox, consent is not possible, and use of living wills to resolve this issue will inevitably result in delegating unbounded discretion, as was once possessed by monarchs, over the life or death of the demented person. But cultural blinders in the form of the myth of “the empty shell” impair our ability to see clearly the horrors that could accompany permitting PAS for dementia. Rebuffing this myth, however, cannot be limited to the standard academic methods of analysis and authority, though there is much of that in this Article. It also requires a visit into the day-to-day world, what some would call reality. The call to reconceptualize the demented must be more than thoughtful and reflective; it must be vivid. To that end, at various points in this Article I tell stories about my mother and her life with dementia.

Part I of this Article explores the neurophysiological effects of dementia on the interrelated processes of memory, cognition, and language. The section then explains how the neurological damage associated with dementia manifests in the daily life of the dementia sufferer. Part II faces the myth of “the empty shell” head on—exploring the myth, debunking it, and then explaining the need to curb the self-fulfilling institutional dynamics of “malignant positioning.” Finally, Part III directly confronts the impossibility of creating a legal regime that can acceptably regulate PAS and dementia.

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AND THE MAKING OF A VAST INDUSTRY 378 (1982); Dieter Giesen, *Dilemmas at Life's End: A Comparative Legal Perspective*, in EUTHANASIA EXAMINED: ETHICAL, CLINICAL AND LEGAL PERSPECTIVES 200 (John Keown ed., 1995) [hereinafter EUTHANASIA EXAMINED]; Sheryl A. Russ, *Care of the Older Person: The Ethical Challenge of American Medicine*, 4 ISSUES L. & MED. 87, 88 (1989).



## I

## THE SCIENCE AND RESULTING EFFECTS OF DEMENTIA

A. *The Science of the Brain*

Dementia results from damage to the “neural architecture” of various areas of the brain.<sup>31</sup> As a disease such as Alzheimer’s breaks down various aspects of the structure of brain cells,<sup>32</sup> deficiencies in assorted neurotransmitters (chemicals that send messages from one cell to the next<sup>33</sup>) appear.

The brain is the center of the interrelated processes of language, memory, and communication.<sup>34</sup> Language is a system of symbols used to communicate;<sup>35</sup> the system itself is composed of different varieties of knowledge.<sup>36</sup> The dementia sufferer will experience different language deficits depending of the site of the neurological damage.<sup>37</sup>

Linguistic communication requires more than access to language. It is also a result of cognition; specifically, it is a cognitive process of sharing ideas through language.<sup>38</sup> Cognition, in turn, implicates stored knowledge as well as the processes for making and manipulating knowledge. The human brain is a pattern recognition system.<sup>39</sup> This system thus depends on memories stored in patterns,<sup>40</sup> and it is in the domain of memory<sup>41</sup> where dementia-causing diseases do damage.<sup>42</sup>

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<sup>31</sup> See MACE & RABINS, *supra* note 18, at 31; see also BAYLES & TOMOEDA, *supra* note 1, at 69; Hughes et al., *supra* note 15, at 1.

<sup>32</sup> See BAYLES & TOMOEDA, *supra* note 1, at 56–57.

<sup>33</sup> See MACE & RABINS, *supra* note 18, at 302.

<sup>34</sup> *Id.* at 23.

<sup>35</sup> See *id.* at 35.

<sup>36</sup> See *id.*

<sup>37</sup> See *id.* at 23.

<sup>38</sup> Meaningful communication requires the production and comprehension of ideas. The act of speaking, in and of itself, does not constitute communication because that which is spoken may be structurally and semantically meaningless. Nor does knowing the grammar of a language ensure the ability to communicate. One can know the rules for combining sounds into words, and words with each other, without being able to intentionally communicate. Communication occurs only when sounds and words have been structured in such a way that the idea of the speaker is derived by the listener. *Id.* at 35–40.

<sup>39</sup> See *id.* at 23.

<sup>40</sup> See *id.* at 24.

<sup>41</sup> See *id.* at 28–29; Hughes et al., *supra* note 15, at 1.

<sup>42</sup> As such, dementia is one cause of aphasia, an “acquired impairment of language” from stroke, trauma, or disease. See BAYLES & TOMOEDA, *supra* note 1, at 28.

Our many memory systems<sup>43</sup> operate on different rules<sup>44</sup> with distinct neural architecture.<sup>45</sup> Sensory memory holds information from our senses long enough so that other brain systems can review that data for further processing.<sup>46</sup> Short-term memory refers to the amount of information that can be held in consciousness.<sup>47</sup> Contrary to those who use the term to refer to any information obtained in the past few years (“We went to that restaurant less than a year ago and I can’t even remember where it was located—where has my short-term memory gone?”), short-term memory does not refer to information that recently fell from consciousness. Once a memory is no longer in consciousness, even if it was three minutes ago, it resides in long-term memory.<sup>48</sup>

Working memory is active; it is what you are thinking about now.<sup>49</sup> Working memory also exhibits an active, decision-making aspect—the so-called “central executive.”<sup>50</sup>

To interpret new information, we rely on previous experience. Thus, working memory must activate past experience and bring that knowledge to consciousness. Generally, decisions must be made about the new information the organism is receiving. Baddeley called the decision-making component of working memory the *central executive*. The central executive system focuses attention, encodes information, retrieves information from long-term stores, plans action, and solves problems.<sup>51</sup>

A different aspect of memory, semantic memory, stores concepts.<sup>52</sup> Within semantic memory one finds schema—“an attentional set formed by the simultaneous activation of a group of related concepts”<sup>53</sup>—that we carry for a seemingly endless set of activities (e.g., we have schema for eating at a Chinese restaurant, going through security at an airport, putting gas in an automobile, using a cell phone, etc.).<sup>54</sup>

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<sup>43</sup> *Id.* at 37.

<sup>44</sup> *Id.* at 38.

<sup>45</sup> *Id.* at 50.

<sup>46</sup> *Id.* at 37–38.

<sup>47</sup> *Id.* at 38–39.

<sup>48</sup> *Id.* at 39.

<sup>49</sup> *Id.* at 38.

<sup>50</sup> *Id.* at 39.

<sup>51</sup> *Id.*

<sup>52</sup> *Id.* at 40.

<sup>53</sup> *Id.* at 41.

<sup>54</sup> *Id.*

This accounts for how a person with advanced Alzheimer's can walk straight into a piece of furniture even though the brain clearly perceives it. Semantic memory simply did not retrieve the concept of furniture or the related schema of how to move through a furnished space.<sup>55</sup> I got a sense of this phenomenon last year. I ran a red light (fortunately, no other cars were present). I looked at the light and plainly saw it was red, but in that instant, my brain did not retrieve the construct that seeing a red orb equals applying pressure to the brake.

Episodic memory contains events (e.g., I met my son for coffee yesterday, I covered propensity evidence in last Thursday's class, my wife and I spent our anniversary away at the ocean last month).<sup>56</sup> Lexical memory contains words,<sup>57</sup> while nondeclarative memory guides motor skills so one does not have to constantly learn how to walk or tie one's shoes.<sup>58</sup>

Dementia compromises all memory systems; damage to the frontal lobe and systems providing input to the frontal lobe is common. Thus, the person with Alzheimer's loses working and episodic memory first, followed by loss of semantic memory.<sup>59</sup>

*B. The Effect on the Individual Resulting from Damage to the Brain by Dementia-Causing Disease*

Any discussion of the effect and impact of a dementia-causing disease on the individual necessarily proceeds in the form of generalization. We are talking about *individuals*. People with dementia do not exhibit all the symptomology that reports of caregivers associate with dementia, and those behaviors the individual does manifest do not often last for the entire term of the disease.<sup>60</sup> In fact, many are temporary, although often followed by new, equally difficult behavior.<sup>61</sup> That said, there are common patterns nonetheless.

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<sup>55</sup> See MACE & RABINS, *supra* note 18, at 108.

<sup>56</sup> BAYLES & TOMEDA, *supra* note 1, at 42.

<sup>57</sup> *Id.* at 51.

<sup>58</sup> *Id.*

<sup>59</sup> *Id.* at 5, 69.

<sup>60</sup> MARKUT & CRANE, *supra* note 18, at 66; BAYLES & TOMOEDA, *supra* note 1, at 36 (explaining that the precise cognitive-communication deficits will partly be a function of the area of the brain damaged); MACE & RABINS, *supra* note 18, at 23 (discussing that different cognitive abilities are affected "unevenly," and consequently, the person with dementia is able to do some things competently, but not others).

<sup>61</sup> See MARKUT & CRANE, *supra* note 18, at 66.

Consider the implications of the previous section for the dementia sufferer.

The production and comprehension of language cannot be separated from cognition. Rather, communication is a manifestation of cognition. Persons with dementia have trouble producing linguistic information because they have trouble thinking and generating and ordering ideas, in part because information-processing capabilities of declarative and working memory systems are disturbed, in part because of degradation of knowledge. These same individuals have difficulty comprehending language because of deficits in the cognitive processes of perception, recognition,<sup>62</sup> attention, inferencing memory, and degradation of knowledge.

For those in the early stages of Alzheimer's disease (which this Article will focus on because it is the most common cause of dementia), the episodic memory constantly fails—getting lost while walking or on a drive,<sup>63</sup> forgetting to take medicine, forgetting what they were talking about, repeating the same story they told an hour ago. Lexical memory's degradation leaves a formerly articulate person struggling to find appropriate words<sup>64</sup> with increasing use of imprecise “empty words” like “thing” and “it.”<sup>65</sup> Asking where a family member with dementia placed a red enamel Dutch oven may in the course of a lexical struggle emerge as “the red cooking thing.” This experience is described by dementia sufferers:

For a while, I'll search for a word and I can see it walking away from me. It gets littler and littler. It always comes back, but at the wrong time. You can't be spontaneous.

. . . .

I really can't converse very well at all. So that's very limiting. I can't think of things to say before somebody's already said it and they've superseded what I have to say. The words get tangled very easily and I get frustrated when I can't think of a word. Every time I converse with somebody, there's always some word I can't remember. I really cuss when I can't remember a word.

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<sup>62</sup> BAYLES & TOMOEDA, *supra* note 1, at 47.

<sup>63</sup> *Id.* at 42; *see also id.* at 47 (explaining that those with dementia forget what they just heard, read, or thought).

<sup>64</sup> *See* MACE & RABINS, *supra* note 18, at 35; *see also* BAYLES & TOMOEDA, *supra* note 1, at 60 (stating that in mid-stage Alzheimer's, the difficulty of finding words becomes more obvious in spontaneous speech).

<sup>65</sup> BAYLES & TOMOEDA, *supra* note 1, at 66.

I'm aware that I'm losing larger and larger chunks of memory... I lose one word and then I can't come up with the rest of the sentence. I just stop talking and people think something is really wrong with me.<sup>66</sup>

Imagine how upsetting it would be to watch the progressive loss of your competencies,<sup>67</sup> to give up your independence (e.g., being denied the right to drive),<sup>68</sup> your responsibilities and accompanying social roles,<sup>69</sup> and your positions of leadership in the family.<sup>70</sup> Not surprisingly, the demented individual starts to exhibit anger, irritability, and confusion and becomes frightened.<sup>71</sup>

Usually at this time of the school year, when I come home from work, Martha has changed out of her school clothes, has a load of laundry in the washer, dinner on the stove, and is finishing scoring the tests of the children she worked with today. But lately the scene is different. When I come in, she is sitting at the table in her school clothes. There is no laundry going, nothing on the stove. Piles of crumpled papers surround her on the table and floor on which she has unsuccessfully tried to record and compute test scores. She has been unable to use the charts and do the straightforward computations that she has done for years. She is frustrated, angry, frightened. She shouts; she cries. I help her do the calculations and even rewrite some of the summaries she has struggled with. She calms down somewhat but is still very upset. "What's wrong with me?" she asks. I can't answer because I don't know, but we both know that something is very wrong, and we are afraid.<sup>72</sup>

Also not surprisingly, persons with dementia become increasingly unsure, losing the sense that they can trust themselves in the world. All they want is for things to be normal again, to be like how they were.<sup>73</sup>

Being unsure is an experience wherein people can no longer take themselves for granted in how they are in the world.<sup>74</sup> They are

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<sup>66</sup> Lisa Snyder, *Personhood and Interpersonal Communication in Dementia*, in DEMENTIA, *supra* note 2, at 259, 261 (citations omitted) (quoting various accounts).

<sup>67</sup> See MACE & RABINS, *supra* note 18, at 30; Catherine Oppenheimer, *I Am, Thou Art: Personal Identity in Dementia*, in DEMENTIA, *supra* note 2, at 193, 197.

<sup>68</sup> See MARKUT & CRANE, *supra* note 18, at 84–88; Oppenheimer, *supra* note 67, at 197.

<sup>69</sup> See Oppenheimer, *supra* note 67, at 197 (observing that dementia takes away the individual's previously held social roles).

<sup>70</sup> See MACE & RABINS, *supra* note 18, at 142.

<sup>71</sup> See *id.* at 207.

<sup>72</sup> MARKUT & CRANE, *supra* note 18, at 3.

<sup>73</sup> See *id.* at 12.

<sup>74</sup> Phinney, *supra* note 18, at 11.

often unsure of themselves<sup>75</sup> and are not fully at ease as they live their day-to-day lives . . . .

In the middle stage of Alzheimer's, the individual changes most dramatically, "becoming more dependent on others for survival."<sup>76</sup> The person becomes disoriented as to place in addition to time,<sup>77</sup> not recognizing where he or she is. Increasingly, the deficits in various memory systems make spontaneous speech more and more difficult<sup>78</sup> and interfere with the ability to comprehend and retain explanations.<sup>79</sup> Without a competent executive function in working memory, the person can no longer make plans and act on them.<sup>80</sup> For even in the unlikely event such a plan was made, working memory would be unable to retrieve it from long-term memory.

With a loss of orientation as to space, the familiar becomes alien. It is no wonder dementia sufferers begin to hoard and hide food.<sup>81</sup> They are surrounded by strangers they do not understand. Paranoia—accusing family of stealing possessions<sup>82</sup>—makes complete sense. You do not remember where you put or hid some possession, and do not recall some family member's explanation an hour earlier about where it had gone.<sup>83</sup> At some point in the disease, it becomes very hard to make a person feel safe in that person's own home.<sup>84</sup>

*A person's feelings also affect his behavior.* The person with dementia probably feels lost, worried, anxious, vulnerable, and helpless much of the time. He may also be aware that he fails at tasks and feel that he is making a fool of himself. Imagine what it must feel like to want to say something nice to your caregiver but all that comes out are curse words. Think how frightening it must be if a familiar home and familiar people now seem strange and unfamiliar.<sup>85</sup>

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<sup>75</sup> *Id.*

<sup>76</sup> See BAYLES & TOMOEDA, *supra* note 1, at 65.

<sup>77</sup> *Id.*

<sup>78</sup> See BAYLES & TOMOEDA, *supra* note 1, at 67; Snyder, *supra* note 66, at 261.

<sup>79</sup> See MACE & RABINS, *supra* note 18, at 38; *see also id.* at 25 (explaining that a demented person will only comprehend or recall part of a conversation and then act on that part, responding to what they think was said).

<sup>80</sup> See MACE & RABINS, *supra* note 18, at 28; MARKUT & CRANE, *supra* note 18, at 84.

<sup>81</sup> See MACE & RABINS, *supra* note 18, at 68, 133.

<sup>82</sup> *Id.* at 155.

<sup>83</sup> *Id.* at 159–60; *see also id.* at 38 (describing that it becomes increasingly difficult for the demented individual to understand explanation).

<sup>84</sup> See MARKUT & CRANE, *supra* note 18, at 119.

<sup>85</sup> MACE & RABINS, *supra* note 18, at 24.

During the late stages of Alzheimer's, the individual can become disoriented as to person (i.e., does not know who he or she is),<sup>86</sup> as well as place and time. The sufferer might be unable to speak more than one or two words<sup>87</sup> "and may recognize no one or only one or two people."<sup>88</sup> This person will be unable to walk, having lost nondeclarative memory<sup>89</sup> or to care for themselves in any way.<sup>90</sup> "There is incontinence of bladder and bowel. Intellect is devastated by a global failure of working and declarative memory systems and individuals are unable to carry out basic ADLs,"<sup>91</sup> forgetting even how to swallow or eat.<sup>92</sup>

In the end, the nervous system fails, resulting in death.<sup>93</sup> The cause of death is dementia.<sup>94</sup>

## II

### EXPOSING THE CULTURAL BLINDERS THAT IMPAIR OUR ABILITY TO PERCEIVE THE REALITY OF PAS AND DEMENTIA—THE MYTH, REJECTING THE MYTH, AND COMBATING SELF-FULFILLING DYNAMICS

#### A. *The Myth of the "Empty Shell"*

It is common for people in our culture to see the severely demented as being dead or as good as dead.<sup>95</sup> Intelligent people have described

<sup>86</sup> See BAYLES & TOMOEDA, *supra* note 1, at 67.

<sup>87</sup> See MACE & RABINS, *supra* note 18, at 36.

<sup>88</sup> *Id.* at 291; MARKUT & CRANE, *supra* note 18, at 56 (discussing that demented individuals may get to the "point where they do not recognize the people around them").

<sup>89</sup> See MACE & RABINS, *supra* note 18, at 90–92.

<sup>90</sup> See BAYLES & TOMOEDA, *supra* note 1, at 67 (explaining that demented individuals "are unable to carry out basic ADLs").

<sup>91</sup> "ADLs" refers to "activities of daily living" (dressing, bathing, grooming, and such). See Elaine M. Brody et al., *Excess Disabilities of Mentally Impaired Aged: Impact of Individualized Treatment*, 25 GERONTOLOGIST 124, 127 (1971). For further description of early-stage dementia, see A.F. JORM, *THE EPIDEMIOLOGY OF ALZHEIMER'S DISEASE AND RELATED DISORDERS* 26–27 (1990).

<sup>92</sup> See MACE & RABINS, *supra* note 18, at 72.

<sup>93</sup> *Id.* at 113.

<sup>94</sup> *Id.* at 114; see also *id.* at 291 (explaining that the natural progression of Alzheimer's disease usually ends in death). It is difficult, however, to determine the point at which the Alzheimer's sufferer becomes "terminal." See *id.*

<sup>95</sup> Alison Phinney, *Fluctuating Awareness and the Breakdown of the Illness Narrative in Dementia*, 1 DEMENTIA 329, 338–40 (2002); see also A. Harry Lesser, *Dementia and Personal Identity*, in DEMENTIA, *supra* note 2, at 55, 57 (explaining caregivers say things like "[h]e's not there any more"); Eric Matthews, *Dementia and the Identity of the Person*, in DEMENTIA, *supra* note 2, at 163, 163.

the demented as being no more than an empty shell or living a cabbage-like existence.<sup>96</sup>

Those suffering from severe dementia are easily viewed as mere “shells” of their former selves. Philosopher John Arras has made use of this metaphor to describe an elderly demented woman: “Unfortunately, she appears to have been reduced to a mere shell of her former self. She can no longer reason, communicate (except in the most rudimentary, reflexive manner), relate to her family, or experience the manifestations of love.” Arras concludes that she “continues to have biological life, but her *biographical* life has come to an end.”<sup>97</sup>

Think about what these public sentiments really mean. Beaches are littered with empty shells. Perhaps we will take note of a particularly shiny or pretty one, but it is still just an empty shell. We could as easily ignore it, try to skip it along the water, or step on it and crush it. It is just an empty shell. Now think about the “life” of a cabbage. It is a vegetable. It sits on the ground, rooted in dirt, and rots unless we choose to pick it and dice it for coleslaw. We feel no emotion, no feeling in connection with a cabbage. This idea that the human “self” is *lost* with dementia pervades our culture.

The loss of mind in ‘dementia’ reflects the common and distressing observation by relatives, carers, and doctors that ‘self’ is lost slowly as the illness progresses. The scientific and popular literature has largely reflected this concept with books such as *The Loss of Self* (Cohen & Eisdorfer 2001) or *Alzheimer’s Disease: Coping with a Living Death* (Woods 1989). Films like *Iris*, . . . showing the deterioration of the author and philosopher Iris Murdoch, and media reports describing the illness of the late US

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<sup>96</sup> Hughes et al., *supra* note 15, at 9.

<sup>97</sup> Post, *supra* note 21, at 715 (quoting John D. Arras, *The Severely Demented, Minimally Functional Patient: An Ethical Analysis*, 36 J. AM. GERIATRIC SOC’Y 938, 941 (1988)). Some philosophers have viewed the severely demented as mere “shells,” individuals who possess “biological life,” not “biographical life.” See *id.*; JAMES RACHELS, *THE END OF LIFE: THE MORALITY OF EUTHANASIA* 50 (1986) (sharing the view that only biographical life has the quality of a true life worthy of moral consideration).

In response to Arras and Rachels, Stephen G. Post argues:

“A mere shell” implies that there is nothing present within, but the metaphor obscures the continued presence of the patient’s affective core and the uncertainties of determining radical cognitive devastation. Severely demented older persons are, after all, neither brain dead nor in a persistent vegetative state. We might wonder, and not incidentally, whether cognition is any more important than affection in determining personhood.

Post, *supra* note 21, at 716.



President Ronald Reagan, have continued to reinforce the idea of the *annihilation of self* in people's minds.<sup>98</sup>

We are a culture of youth, where the latest techno-toy is what matters. In this world of "new-worship," the aging already tend to be devalued.<sup>99</sup> On top of this so-called ageism is the widely held cultural narrative of the inevitable journey of the demented from father, mother, friend, child, mentor, and worker to empty shell and cabbage. There would seem to be little sense in constraining the notion of permitting PAS for these (otherwise extremely expensive) cabbages and shells.

This cultural belief system, moreover, does not merely rest on fear and misconception. In the realm of the philosophy of psychiatry,<sup>100</sup> the empty shell myth finds support in a number of philosophical<sup>101</sup> and psychological<sup>102</sup> theories. It is the philosophy of John Locke,

<sup>98</sup> Aquilina & Hughes, *supra* note 20, at 144 (footnote omitted).

<sup>99</sup> See BYTHEWAY, *supra* note 30, at 14, 30–31; Bavidge, *supra* note 2, at 48. For an analysis explaining why the concept that old age is a "second childhood" is both conceptually incorrect and culturally demeaning, see Harry Cayton, *From Childhood to Childhood? Autonomy and Dependence Through the Ages of Life*, in DEMENTIA, *supra* note 2, at 277, 285.

<sup>100</sup> See generally DEMENTIA, *supra* note 2 (presenting an anthology of recent thoughts of major figures in the field of the philosophy of psychiatry).

<sup>101</sup> Philosophically, Cartesians would find no problem, given the fundamental concept of "I think, therefore I am," to conclude within their conception of mind-body dualism that if the mind fails, the self ceases to exist. See ANTHONY KENNY, THE METAPHYSICS OF MIND 17 (1989); Aquilina & Hughes, *supra* note 20, at 151. For the modern dualist stance, see Hughes et al., *supra* note 15, at 8.

A similar conclusion is reached by Kantian philosopher Michael Luntley, albeit by a different analysis. For Luntley, the self is that which "keep[s] track of things." See Michael Luntley, *Keeping Track, Autobiography, and the Conditions for Self-Erosion*, in DEMENTIA, *supra* note 2, at 105, 106. For Luntley, saying "I" may be evidence of, but not sufficient for, personal identity. *Id.* at 106–07. But see Steven R. Sabat & Rom Harré, *The Construction and Deconstruction of Self in Alzheimer's Disease*, 12 AGEING & SOCIETY 443, 445–47 (1998) (explaining that the "self," as represented by the lexical "I," is formal and not dependent on memory). If the use of "I" becomes merely a habit, this will be reflected in discourse. See *id.* at 443 (explaining that empirical evidence indicates that the self "persists far into the end stage of the disease").

For Luntley, these "things" are selected and ordered according to the "point of view" of the self or "I." See Luntley, *supra*, at 110.

If, in theory, one could no longer "keep track of things" (as might be the case in later stages of dementia), the self would cease to exist. *Id.* at 106. But see *supra* note 97 and accompanying text.

<sup>102</sup> In the field of cognivist psychology, all meaning making takes place inside the skull of the individual. See ALAN J. PARKIN, EXPLORATIONS IN COGNITIVE NEUROPSYCHOLOGY 3 (1996); see also Tim Thornton, *The Discursive Turn, Social Constructionism, and Dementia*, in DEMENTIA, *supra* note 2, at 123. Cognitivists can also accept many postmodern concepts involving social construction of meaning. They accept

however, that provides the most commonly relied upon intellectual support for the empty shell myth.

For Locke, it was not sufficient that the subject had a biological existence or even was a thinking entity (for animals also think).<sup>103</sup> A person must be capable of self-reflection<sup>104</sup> or, at least to some degree, self-knowledge. Locke defined a “person” as a “thinking intelligent being [that] can consider itself as itself, the same thinking thing, in different times and places.”<sup>105</sup>

Under this definition, when, as occurs with severe dementia, one loses memory of a self in different places in time and even loses orientation as to person,<sup>106</sup> the individual ceases to be a person.<sup>107</sup> Modern Lockceans<sup>108</sup> rely upon Locke’s notion of a person to deny personhood to individuals in a persistent vegetative state.<sup>109</sup>

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that mental states or meanings are caused by social factors. *Id.* at 126. Ultimately, however, for a cognitive psychologist, the effects of such social influences are “mediated by what happens within the skull.” *Id.* Thus, to the extent that under this psychological theory everything happens inside the skull (i.e., the brain), as the brain fails so does the existence of the self whose inner world is shutting down.

<sup>103</sup> See Matthews, *supra* note 95, at 165.

<sup>104</sup> See E. Jonathan Lowe, *Can the Self Disintegrate? Personal Identity, Psychopathology, and Disunities of Consciousness*, in DEMENTIA, *supra* note 2, at 89, 94; Matthews, *supra* note 95, at 165. For modern Lockceans, “persons” are those capable of appreciating their own value. See generally JOHN HARRIS, *THE VALUE OF LIFE* (1985); John Harris, *A Philosophical Case Against the Philosophical Case Against Euthanasia*, in EUTHANASIA EXAMINED, *supra* note 30, at 36, 40–41; John Harris, *Euthanasia and the Value of Life*, in EUTHANASIA EXAMINED, *supra* note 30, at 6 [hereinafter Harris, *The Value of Life*]; John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, in DEATH, DYING, AND EUTHANASIA 139, 174–75 (Dennis J. Horan & David Mall eds., 1977); Joseph Fletcher, *Ethics and Euthanasia*, in DEATH, DYING, AND EUTHANASIA, *supra*, at 293, 295; PETER SINGER, *RETHINKING LIFE AND DEATH: THE COLLAPSE OF OUR TRADITIONAL ETHICS* 183 (1994); Helga Kuhse & Peter Singer, *For Sometimes Letting—and Helping—Die*, 14 L. MED. & HEALTH CARE 149 (1986); Van Rensselaer Potter, *On Dying with Personhood*, in EUTHANASIA: CONTEMPORARY ISSUES COMPANION, at 24–26 (Lisa Yount ed., 2002).

<sup>105</sup> JOHN LOCKE, *AN ESSAY CONCERNING HUMAN UNDERSTANDING* 285. (Peter H. Nidditch ed., Clarendon Press 1975) (1690).

<sup>106</sup> See BAYLES & TOMOEDA, *supra* note 1, at 67.

<sup>107</sup> See Jennifer Radden & Joan M. Fordyce, *Into the Darkness: Losing Identity with Dementia*, in DEMENTIA, *supra* note 2, at 71, 71.

<sup>108</sup> See, e.g., SINGER, *supra* note 104, at 180, 197–98; Harris, *The Value of Life*, *supra* note 104, at 9.

<sup>109</sup> See SINGER, *supra* note 104, at 192, 206–07; Harris, *The Value of Life*, *supra* note 104, at 18.

## B. Rejecting the Myth

### 1. Lessons from Experience

#### a. A Fuller View of the Demented

Among caregivers who work with the demented, increasing numbers report that they do not find any correspondence between the individuals for whom they care and the crude cultural, metaphorical characterizations used like empty shell and cabbage-like. Even when seriously demented, a person can find sources of joy and pleasure.<sup>110</sup> “A dementing illness does not suddenly end a person’s capacity to experience love or joy, nor does it end her ability to laugh.”<sup>111</sup> Like many persons with even severe dementia, my mother took great joy in listening to music<sup>112</sup> and the weekly visits of a friendly dog that was brought to the care facility where she lived.<sup>113</sup>

Caregivers consistently report that they are aware of a “self” in even severely demented individuals.<sup>114</sup> In the first place, even those with more advanced forms of dementia have relatively lucid moments.<sup>115</sup> Particular circumstances or certain times of day may allow a person with memory loss to seem more normal.<sup>116</sup> As one family member with a father-in-law who suffered from dementia noted:

In the few minutes after leaving the Family Alliance day program, when I was driving home with Mike, he would make comments or talk to me in a perfectly normal manner, just like it was you and me, perfectly normal. It would be just for those few minutes and then it was gone. I really treasured those few moments.<sup>117</sup>

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<sup>110</sup> SINGER, *supra* note 104, at 132–34, 299, 370; *see also* Sanford H. Kadish, *Letting Patients Die: Legal and Moral Reflections*, 80 CAL. L. REV. 857, 887 (1992) (observing there is value to the experiences in a demented person’s life); *cf.* Robertson, *supra* note 104, at 176 (explaining that an insane person is still regarded as a “specific” person).

<sup>111</sup> MACE & RABINS, *supra* note 18, at 213.

<sup>112</sup> *See* Oppenheimer, *supra* note 67, at 198.

<sup>113</sup> *See* BAYLES & TOMOEDA, *supra* note 1, at 204 (explaining that positive results are seen when demented persons are provided “something to nurture,” such as pets or plants).

<sup>114</sup> *See* Aquilina & Hughes, *supra* note 20, at 145.

<sup>115</sup> *Id.*; *cf.* Stephen G. Post, *Respectare: Moral Respect for the Lives of the Deeply Forgetful*, in *DEMENTIA*, *supra* note 2, at 223, 230 (noting that a demented person might find coherence in “another time” that can be recalled).

<sup>116</sup> MARKUT & CRANE, *supra* note 18, at 178.

<sup>117</sup> *Id.*

Perhaps dementia is akin to an electrical short where at times you shake the wire just right and the bulb goes on.<sup>118</sup> There were a few times during visits with my mother in her Alzheimer's residence when, for ten or fifteen minutes, we had a relatively normal conversation, punctuated with mom's laughter at the existential absurdity of her condition.<sup>119</sup> Other times, her conversation was gibberish. Could a coherent mom have been trapped inside, generally unable to communicate in expressed language because of the devastation to the systems making such forms of communication possible? At the time I would have said that such a possibility was highly unlikely. But I have since come across a case study that gives me pause. In this study, the dementia patient was given antidementia drugs. In her case, the results were spectacular. From living an existence that many would equate with a cabbage—noncommunicative and seemingly unaware of her environment—the patient regained her communicative faculties.<sup>120</sup> When she did, she was able to recall in detail what had transpired while she was supposedly an empty shell.<sup>121</sup> Was there something unique about her disease? Might she have been misdiagnosed, suffering from something else that mimicked dementia?<sup>122</sup> Who can know? Nonetheless, it serves as a cautionary tale to the practice of quickly categorizing the severely demented as all but inanimate objects.

Beyond issues of what is called rational cognition, caregivers are adamant about feeling a “sense of humanity” in even the most severely demented.<sup>123</sup> Demented persons, regardless of how they may score on tests measuring their cognitive, word, and language

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<sup>118</sup> See MACE & RABINS, *supra* note 18, at 39.

<sup>119</sup> As to the demented person's awareness of the condition, see Thornton, *supra* note 102, at 130. See also Aquilina & Hughes, *supra* note 20, at 151 (“It is certainly the case that people with dementia can be aware of the loss of their capacities and of aspects of their inner selves.”). Iris Murdoch spoke of herself as “sailing into the darkness.” JOHN BAYLEY, *IRIS: A MEMOIR OF IRIS MURDOCH* 179 (1998). But see Phinney, *supra* note 95, at 330 (explaining that a demented person's awareness of their symptoms fluctuates—sometimes they are aware that they are forgetful, other times not).

<sup>120</sup> See Aquilina & Hughes, *supra* note 20, at 150.

<sup>121</sup> *Id.*

<sup>122</sup> Illness or depression can exacerbate the symptoms of dementia. See MACE & RABINS, *supra* note 18, at 293, 310. In fact, even without dementia, depression alone can affect memory. *Id.* at 6. Additionally, some treatable conditions, such as delirium or thyroid problems, can seem like or even cause temporary dementia. See *id.* at 9–10, 14.

<sup>123</sup> See Aquilina & Hughes, *supra* note 20, at 145.

skills, have “an emotional and relational reality,”<sup>124</sup> retaining the ability to make compassionate connections.<sup>125</sup>

The reality is that until the very advanced and even terminal stage of dementia, the person with dementia will usually have sporadically articulated memories of deeply meaningful events and relationships ensconced in long-term memory . . . . Even in the advanced stage of dementia . . . one finds varying degrees of emotional and relational expression, remnants of personality, and even meaningful non-verbal communication (as in the reaching out for a hug).<sup>126</sup>

In fact, those with dementia retain many of their capacities until the very final stages of the disease. In early-stage Alzheimer’s, the individual generally has good recognition memory, can follow a three-stage command, can sustain attention and selectively attend to stimuli, has semantic knowledge intact, can read and comprehend at the sentence level, and can independently perform basic ADLs (using the toilet, bathing, feeding, etc.).<sup>127</sup> In middle-stage Alzheimer’s, the person can follow a two-step command; can sustain attention for limited amounts of time in a low distraction environment; has fair recognition memory; has good grammar, syntax, and social language; can reminisce about tangible stimuli; can comprehend simple statements, yes or no questions, and most choice questions; and generally is able to perform basic ADLs with minimal assistance.<sup>128</sup> Even at late-stage Alzheimer’s, where dementia is severe, the person can generally recognize his or her own name; often can contribute to a conversation; may attend to positive stimuli for short periods; retains some aspects of social language (greetings, leave taking, responding to a compliment); may answer simple yes or no and choice questions; and may feed himself or herself with minimal assistance.<sup>129</sup>

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<sup>124</sup> See Post, *supra* note 115, at 232.

<sup>125</sup> MARKUT & CRANE, *supra* note 18, at 175.

<sup>126</sup> *Id.* at 231; see also Guy A.M. Widdershoven & Ron L.P. Berghmans, *Meaning-Making in Dementia: A Hermeneutic Perspective*, in DEMENTIA, *supra* note 2, at 179, 179 (stating that until very late in the progression of the disease, the demented person can manipulate objects, react to others, and make meaning through expressed moods).

<sup>127</sup> See *supra* note 90.

<sup>128</sup> See BAYLES & TOMOEDA, *supra* note 1, at 223; see also Joseph M. Foley, *The Experience of Being Demented*, in DEMENTIA AND AGING: ETHICS, VALUES, AND POLICY CHOICES 30–43 (Robert H. Binstock et al. eds., 1992).

<sup>129</sup> BAYLES & TOMOEDA, *supra* note 1, at 223; see also Barry Reisberg et al., *The Final Stage of Alzheimer’s Disease: Issues for the Patient, Family, and Professional Community*, in ALZHEIMER’S DISEASE AND RELATED DISORDERS: PSYCHOSOCIAL ISSUES

While these quotes and citations about the full humanity of the dementia sufferer counter the empty shell myth, they do so in an analysis removed from the three-dimensional reality of life with dementia. They lack texture and color; they do not put us face to face with a real human being. Yet it is the lives of real humans that the insidious myth of the empty shell directly impacts. Therefore, I tell a portion of my mother's story to remedy this deficiency in my attack on the myth.<sup>130</sup>

One caution: The human experience unfolds in the prose of narrative; the academic do so in the language of analysis and authority. So the reader must now be prepared for a shift from the academic into the narrative, and then back again into the academic.

*The Story Begins: Mom Loses It*

*Mom's confusion about when or where things happened and who was there when they did, as well as her increasing tendency to suddenly use total nonsense words ("I think it's under the 'flebus.'"), must have been very frustrating and frightening for her, although publicly she dealt with her mental slips by laughing at herself. But it was no laughing matter.*

*I can only imagine what it would be like for some person I did not know who was undergoing the experience of watching her mind breaking down, day by day. Mom, however, I knew. She was extremely bright, extremely capable. A straight "A" student who had secret dreams of medical school, but instead became a housewife. The path of her life was in part the result of her times and the narrow range of expectations foisted on women in America in the 1940s. But it was more complex than that. I was around seventeen-years-old when I inadvertently came across a box of clippings while cleaning a closet. To my utter amazement, my demanding, seemingly humdrum suburban mom, with whom I constantly butted heads over the exalted trivialities of teen existence, had been a ballerina when she met dad. And she'd been a great ballerina—rave reviews from the Paris Opera where she had been the youngest American to ever dance solo, and*

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FOR THE PATIENT, FAMILY, STAFF, AND COMMUNITY 5, 12–16 (Richard Mayeux et al. eds., 1998).

<sup>130</sup> I also tell her story because, for reasons analogous to the methodology of the emerging feminist movement, it is important that such stories—those of dementia—be told. See, e.g., Phyllis Goldfarb, *A Theory-Practice Spiral: The Ethics of Feminism and Clinical Education*, 75 MINN. L. REV. 1599, 1634 (1991) (discussing the centrality of storytelling in the feminist movement).

*equal plaudits from her performance at the Hollywood Bowl. And the pictures. Mom looked like a 1930's movie star. Amazing.*

*Then, in her sixties, Mom suffered a serious heart attack. She recovered but she no longer had her ability to accurately calculate rows of figures in her head. This was the first of a progression of increasingly serious cognitive blows.*

*Within a year or so, Mom was diagnosed with Parkinson's disease. Her increasing confusion, thus, was always attributed to some aspect of her disease or her treatment. Her Sinimet was not the right dosage, her Parkinson's and high blood pressure meds were intersecting, she ate too soon after taking the meds, she ate too late after taking the meds, she ate protein in the morning (Dad's private theory), and on and on. Anything, but anything, was used other than the possibility that Mom was losing her mind. And it was happening for a far, far longer period of time than I realized. My sister Kathy knew long before me after a Florida visit in which Mom hadn't really recognized her the first day. It was Mom's meds, the story went. Always her meds. But Kathy was skeptical. Dad was covering for her, but it was not so obvious. The problem was that Dad always had the annoying habit of speaking for Mom in regular conversation, even when Mom was just fine. Mom, of course, would give him "the look." That was their shtick. So, it was easy for Dad to cover in our weekly phone conversations. Mom would be on the phone, but dad would say, "Your Mom did this or that—didn't you dear." This was annoying, but not unusual, particularly since Mom did not talk much anyway, even in person.*

*The news in 1995 that Dad possibly had fourth-stage pancreatic cancer pushed her over the edge. He was her constant companion of fifty-two years, her caretaker, and her organizer. He loved Mom, rarely leaving her side. He cooked, cleaned, dressed Mom, shopped, paid bills, dealt with investments, organized their social life, dealt with her medications, led her through her daily physical exercise, and made her do memory problems to keep her mind going. Mom fully understood what the diagnosis of pancreatic cancer meant. She was not stupid, even as she became more confused. She saw things for what they were: she was very sick, and her life companion was dying.*

*Even after we all knew dad was dying, Mom would still communicate, and, at times, was clever and intelligent; however, she was terrified, distracted, and confused to an extent far beyond how she had been a few weeks before. I have in my memory what was, for me, an unforgettable image of Mom losing it. Shortly after my folks'*

arrival in Tacoma, Washington, where my wonderful wife Eva and I had brought Mom and Dad to live after the initial diagnosis of cancer, we went out to dinner with my wife's huge family, the whole Beatty clan. Mom sat next to Eva's mom, Bea. Mom loved Bea, and Bea loved Mom. Even today, Bea sometimes wears Mom's red winter coat "just because it makes me feel like she's close by." Mom also loved food, had loved eating for as long as I remember. Perhaps this was a lifelong reaction to food deprivation during her dancing days. But at this dinner, Mom went beyond any norm. For, all of a sudden, there was Mom eating the food off of Bea's plate with her hands, totally oblivious to all but the primal desire for food. Even so, we all attributed this incident to shock—the terrible news, suddenly being snatched from her home, and such. It would be quite awhile before we faced the truth: Mom had dementia.

*Fast Forward a Year: The Alzheimer's Residence*

Over the course of the next year, we moved Mom in and out of three assisted-living facilities.<sup>131</sup> While each had its own story, the bottom line was the same: none was equipped to deal with a resident who was both very mobile and very demented. Finally on the fourth try, we got it right.

The best thing we ever did for Mom was to move her into a nearby residence specifically built, organized, and staffed to serve the needs of residents who had dementia. Mom had her own room along a short corridor of similar rooms. Three similar corridors joined my mother's corridor, spokes funneling into a huge central circle. The circle in turn contained an open dining area, kitchen, and a beautiful common area with comfortable chairs and couches, a television, a cassette player for music, and a huge stone fireplace. Mom thought she lived in a "lovely lodge," and I guess she did.

Unlike any of the previous residences, this was a noninstitutional institution. Breakfast, lunch, and dinner were served at regular hours, but, if you didn't want to get up, that was fine. You could have breakfast at 2:00 p.m. You could have snacks whenever you wanted, and they'd keep stashes of the "private treats" that we bought for Mom and dole them out when she requested.

Most significantly, the entire staff was a well-trained, well-educated, relatively mature group who truly understood dementia. Concerned and compassionate, they just laughed when Mom, who

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<sup>131</sup> It is common for those with dementia to go through several placements. See MARKUT & CRANE, *supra* note 18, at 120–21.



was generally very sweet and funny and genuinely loved by the staff, would open her mouth, and out would come, "Get over here, fat ass." They were knowledgeable; they understood. Mom was demented. They weren't about to take moments like that seriously.

Mom was very happy. The staff played with her, fed her, teased her, hugged and comforted her, kept her clean, and did her hair—a lovely, lovely lodge (expensive, but no more so than the previous three residences).

And Mom had friends, though their conversations would resemble two televisions on different channels facing each other. The women "shopped" together. They would get dressed up, grab their purses, and catch the bus to the stores. (I learned this from asking a group of women who were standing together in the residence how they were doing. "Fine." One said, "But we have to go now, our bus is here." The rest of the women nodded.) Then they'd go down the corridors and peek in unlocked rooms (once, one such shopper, while pointing to a particular room, told Eva, "I wouldn't waste your time there, nothing really to buy—and what there is, is too expensive.").

Also, Mom loved animals, and Mom loved music. Once a week, to Mom's delight, they'd bring a dog by, and once a week musical performers would entertain the demented audience. It was quite wonderful.

When I'd visit, women would come up to me and start talking, thinking I was their son or some other relation. The men (sadly, some younger than me) would take me aside to let me know that I could count on them completely if I "ever needed insurance" or "needed help even with my investment portfolio." They continued the lives they had known.

Mom wouldn't always recognize me when I came in (whether the result of the dementia or the fact she somehow lost her glasses when she moved in, I cannot say). But when she heard my voice, even from a considerable distance, she'd stand up, look around, and say, "I hear Johnny's voice."

A few times, we had conversations that were both coherent and fairly in touch with reality. Other times, she'd be confused and would laugh and laugh at how out of it she was. It was strange, like her coherent self was taking a bemused look at her demented self. We took her out for ice cream a few times, and it was fun for her. But it was also extremely difficult to get in and out of the car, and she often got disoriented and upset when we returned.

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*She'd laugh when I'd read through the postcards and letters my sister, Kathy, regularly sent her—"That little devil, Kathy, she's a pistol, isn't she?" Often, she was totally coherent; it's just that she was what could be fairly characterized as a psychological time traveler. One day, she was with Dad in the war; another, going out for an evening at a club with a group of young friends in the 1950s; or she would relate a discussion she "just" had with a 1960s neighbor.*

*I also saw my Mom in love. One time, Eva and I came into the main room. Mom was sitting by herself in a big soft chair, a mischievous grin on her face. "I've got a secret." Her entire voice and affect was of a young woman. Finally, we worked through the coyness and giggles and found out that she had just gotten engaged to my father. It was 1941, and she was a twenty-four-year-old girl in love. Amazing, to see my own mother in love.*

#### *Mom Reaches the End*

*In her second year at the Alzheimer's residence, Mom developed ulcers on several parts of her body. As much as the specialist and the residence staff tried, and they tried very hard, they could not get the ulcers under control. Mom had trouble walking and she had trouble getting comfortable when lying down. She lived in constant pain, moaning and whimpering. It was really heartbreaking.*

*She also stopped eating. The staff tried to feed her the best they could, but, within a relatively short time, Mom lost between forty and fifty pounds, back to her weight when she was an eighteen-year-old dancer. That's part of the final course of Alzheimer's. People, even people who loved food as much as Mom, stop eating. Maybe they lose interest, maybe they forget how, or maybe a little of both.*

*As Mom's pain continued, essentially unabated, we decided to have her taken to the hospital for treatment. The residence arranged for an ambulance. When the ambulance arrived and Mom was wheeled out, she was in a happy mood, waving goodbye to everyone. When I met the ambulance twenty minutes later and they wheeled Mom out, she was completely unresponsive. She was the same when they set her up in a room. She never regained consciousness, dying within the week.*

*b. Non-Lockean Philosophy and Noncognitive Psychology Buttress the View that Most Persons with Dementia Are Fully Persons Who Retain a Personal Identity*

Locke's view of what constitutes a "person" has long been attacked on its own terms. For Locke, self-awareness is the essence of being a person, but as other scholars have pointed out, even the most extreme narcissist does not think of himself or herself all of the time.<sup>132</sup> Logically, for there to be a self upon which to reflect, there must already have been a self in existence prior to that reflection.<sup>133</sup> As a result, the "self" cannot solely be a product of that reflection. Also, there is nothing to explain why one would collect the particular bundle of ideas that constitute self-awareness to store in one's brain in the first place. What would give these ideas preferential meaning? What accounts for the creation, existence, and perpetuation of the perceiver's "point of view" in the Lockean theory of personhood?<sup>134</sup>

Most convincingly among the traditional attacks on Locke is that we consider infants to be persons,<sup>135</sup> and they possess none of the self-reflection or memory capacities Locke ascribes as definitionally necessary to be considered a person. One could answer that we consider the infant to be a person, not based on its current state, but rather our understanding that it is on a developmental path that inevitably will lead it to having the capacities to be a Lockean "person." In other words, if it forever stayed in its infant form—if it were a sub-species called "infants"—it would not be a person. But I would disagree. I have a grandchild who is eighteen months old at the time I am writing this. I do not think he has a self-reflected sense of self, and in all likelihood, he will have no memory of this stage of his life. Still, he is my favorite person in the world to spend time with—the funniest, most entertaining, most purely loving person I have ever known.

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<sup>132</sup> Matthews, *supra* note 95, at 171.

<sup>133</sup> *Id.* at 170–71. In fact, under the classic metaphysical view, a person is not manifested by a self-reflecting consciousness, but rather by a soul that persists over time. See, e.g., JOHN H. LEITH, BASIC CHRISTIAN DOCTRINE 112 (1993) ("Karl Barth defined the soul as the person or the self in all of its powers and reasoning, of willing, of self-transcendence. . . . The soul is the self that contemplates the self and organizes all the energies and vitalities of life for freely chosen goals." (footnote omitted)).

<sup>134</sup> For a discussion concerning why modern Lockeans lack a satisfactory explanation for "point of view," see Luntley, *supra* note 101, at 109–12.

<sup>135</sup> See Matthews, *supra* note 95, at 171.

But the significance of non-Lockean philosophers for our purposes is not their philosophical attacks on Locke's premises. Rather, their significance emerges in their rejection of the idea that the person is solely the function of the internal, that the subjective is housed solely within. Though the philosophical positions vary, and even at times come into disagreement, all these philosophers posit a notion of self that, at least in part, is a function of the *external*. For them, mind is formed in *relationship* with others and "the world." This philosophical move, which might be termed "externalism," has serious implications for how we view the personhood and personal identity of dementia sufferers.

Externalism . . . is a thesis about the relation between the mind and the world: it says that the world enters constitutively into the individuation of states of mind; mind and world are not, according to externalism, metaphysically independent categories, sliding smoothly past each other.<sup>136</sup>

The point of "externalism" as a philosophical perspective in all its variations is that our personhood and identity is in great part public and can be publicly maintained even with diminished capacities. This is best illustrated by the broadly held notion that personal identity is a creation of narrative, the story of who we are.<sup>137</sup> This creation is an active process entailing the "*on-going* integration of possible perspectives and versions of who an individual is into a coherent and meaningful life story."<sup>138</sup> It is a mixture of fact and fiction, journalism and movie making, in part a process of identifying with the values, norms, and such of a particular community.<sup>139</sup> But these stories are in no sense solely the work of the individual. These identities are constituted "by a complex interaction between first-, second-, and third-person perspectives."<sup>140</sup> Other people and society will place constraints and limitations on the stories the self-narrator can tell.<sup>141</sup>

<sup>136</sup> COLIN MCGINN, MENTAL CONTENT 9 (1989); *see also* Hughes et al., *supra* note 15, at 16.

<sup>137</sup> *See* Grant Gillett, *Cognition: Brain Pain: Psychotic Cognition, Hallucinations, and Delusions*, in THE PHILOSOPHY OF PSYCHIATRY: A COMPANION 21, 29–30 (Jennifer Radden ed., 2004).

<sup>138</sup> Radden & Fordyce, *supra* note 107, at 74.

<sup>139</sup> *Id.*

<sup>140</sup> *Id.* *See generally* HILDE LINDEMANN NELSON, DAMAGED IDENTITIES, NARRATIVE REPAIR (2001).

<sup>141</sup> *See* Radden & Fordyce, *supra* note 107, at 74–75.

The shape of our lives [i.e., a beginning, middle, and ending that makes some sort of sense] is, at least in part, a function of our imagination and choices. But we do not act in a vacuum. There are biological structures within which we think and act and there are social structures which determine the options we take ourselves to have.<sup>142</sup>

Even when we lose the cognitive capacity to recall, tell, or add to our own story, it can still exist through third parties.<sup>143</sup> Thus, others can support a person's identity even when that person no longer can create their own narrative.<sup>144</sup> These are not stories told at one's funeral or afterwards. These are stories of the individual who is physically embodied in his or her own existence. As such, it affects how we perceive the demented individual before us. Plainly, the individual's narrative is weakened, but this is something we must accept when confronting dementia.<sup>145</sup> While no longer the author in a full sense, the demented person is nonetheless the subject of the story.<sup>146</sup>

Identity through the "webs of interlocation"<sup>147</sup> within which we live is a variant on narrative. I am John Mitchell, son of Lenore and Jim; brother to Kathy; husband to Eva; father to David and Sarah; friend to Mehmet; colleague to Anne, Marilyn, and Annette; teacher of evidence; student of John Kaplan; graduate from Stanford Law School in 1970; and so on. An analogous conception was expressed as follows:

My self-definition is understood as an answer to the question Who I am. And this question finds its original sense in the interchange of speakers. I define who I am by defining where I speak from, in the family tree, in social space, in the geography of social statuses and functions, in my intimate relations to the ones I love, and also

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<sup>142</sup> Bavidge, *supra* note 2, at 42.

<sup>143</sup> See F. Brian Allen & Peter G. Coleman, *Spiritual Perspectives on the Person with Dementia: Identity and Personhood*, in *DEMENTIA*, *supra* note 2, at 205, 216; John McMillan, *Identity, Self, and Dementia*, in *DEMENTIA*, *supra* note 2, at 63, 69; Oppenheimer, *supra* note 67, at 200 (explaining that family members hold pieces of the demented person's identity through history, mannerisms, etc.).

<sup>144</sup> See Aquilina & Hughes, *supra* note 20, at 152; Radden & Fordyce, *supra* note 107, at 83.

<sup>145</sup> See Radden & Fordyce, *supra* note 107, at 84.

<sup>146</sup> See *id.* In contrast to the third-person storyteller, as a result of the fluctuating awareness of their symptoms, the "story" of her disease is a "narrative of chaos." See Phinney, *supra* note 95, at 340–41.

<sup>147</sup> See McMillan, *supra* note 143, at 66–67.

crucially in the space of moral and spiritual orientation within which my most important defining relations are lived out.<sup>148</sup>

Such a view of personal identity, as an interconnected web of exterior relationships, plainly exists outside the inner world of the individual (although exact knowledge of precisely what these relationships “mean” to the individual may be difficult to access in the case of the demented person). The identity persists regardless of cognitive failure.<sup>149</sup>

However, could one use these same theories of social construction and intersubjectivity, which have been posited to *maintain* the personal identity of the demented person, to conclude that a particular individual *lacks* such a personal identity? If we are talking only about empirical observations of discrete individuals, the answer may well be yes. My family and I interacted with my mother and shared her stories, and thus were part of her webs of interlocution. But imagine a severely demented person who has no one. They stare into space in a state geriatric ward. No one interacts with them, is aware of them, and carries their story. Under our intersubjective, narrative, and social construction and webs of interlocution theories, has this individual not lost personal identity? I do not believe so because I do not believe that when applied to the demented, these theories are merely empirical descriptions of particular factual instances. Rather, these theories are imbued with normativity.

A solitary, demented individual is a human being. To allow his or her limited capacity to preserve a semblance of a personal identity to be extinguished for lack of any social support is factually understandable but unpardonable. However constricted, he or she can continue to exist as an individual if a caregiver pays attention—a touch, a look, a fragile web enveloping a person outside of the

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<sup>148</sup> See CHARLES TAYLOR, *SOURCES OF THE SELF: THE MAKING OF THE MODERN IDENTITY* 35 (1989).

<sup>149</sup> There is a final theory of identity sameness, which, unlike the others previously discussed, does not concern the nature of making meaning. It focuses on the nature of being human. Under this view, humans are inherently “bounded beings.” See Lesser, *supra* note 95, at 59. We are born, grow, decline, and die. We always are changing from our past and into our future. See *id.* An essential feature of our identity is that we will decline. As part of that we may have vascular problems or we may get lucky and never experience any coronary difficulties. We may develop dementia or we could be lucky and die with our minds relatively intact. The point is that in our inevitable decline, one of the possibilities we could suffer is dementia. This range of possible ways to decline has always been essentially defining who we were as human beings—beings whose decline could take one of a widely ranging set of paths. Dementia is just one such path; the person is still the same (bounded by the inevitability of some narrative of decline).

individual who looks and thinks: “This is the person who likes apple sauce, the person who pissed on the floor and tried to clean it with her dress, the person who had the hiccups when the handbell choir came over to perform.” As a decent society, we owe demented individuals at least that level of care under any circumstances, particularly if their circumstances are the reflection of the “self-fulfilling dynamics” carefully explored in the next section of this Article.

Professor Martha C. Nussbaum takes an analogous tack in her profound book, *Frontiers of Justice: Disability, Nationality, Species Membership*.<sup>150</sup> Nussbaum suggests an approach to establishing a just society that meets what she perceives to be deficiencies in John Rawls’s contractarian approach<sup>151</sup> when dealing with the place of the mentally disabled.<sup>152</sup> She does not discuss dementia, but her ideas are quite applicable to this area. In place of Rawls’s procedural approach to establishing such a society, Nussbaum focuses on a societal obligation to support a minimum level of development of a set of “capabilities” she believes necessary to live a life of human dignity.<sup>153</sup> These capabilities include life, bodily health, affiliation, and control over one’s environment.<sup>154</sup> In the case of the mentally or physically disabled, these requirements for a life of human dignity, and thus a just society in Nussbaum’s view, place broad obligations on the body politic to ensure the individual develops all their capabilities:

[T]he Rawlsian emphasis on income and wealth suggests that the relevant resources are items that we can distribute to individuals. Sen’s critique does not explicitly dispute this. Give the person in the wheelchair enough money, he seems to say, and he will be able to move from here to there; the only problem is to determine the amount of money. This reply is insufficient. No matter how much money we give the person in the wheelchair, he will still not have adequate access to public space unless public space itself is redesigned. Maybe a very rich person could afford a full-time chauffeur and a set of bearers who could carry him up the stairs of rampless buildings. But even if making people with impairments that rich were a sensible goal of public policy, as it is not, we would still have not gotten to the root of the matter, which is that this

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<sup>150</sup> See generally MARTHA C. NUSSBAUM, *FRONTIERS OF JUSTICE: DISABILITY, NATIONALITY, SPECIES MEMBERSHIP* (2006).

<sup>151</sup> See generally JOHN RAWLS, *A THEORY OF JUSTICE* (1971) (discussing a contractarian approach to justice).

<sup>152</sup> See NUSSBAUM, *supra* note 150, at 98–99.

<sup>153</sup> See *id.* at 70.

<sup>154</sup> *Id.* at 76–78.

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person should not *have* to rely on a chauffeur or on bearers. There should be wheelchair access on buses and sidewalks, and all buildings<sup>155</sup> should have ramps and wheelchair-accessible elevators.

Perhaps, analogous to Nussbaum's example of the person in the wheelchair, our society likewise should provide resources for meaningful caregiving for the demented. Governmental obligations aside, as fellow human beings we cannot ethically allow the identity of a demented person, stagnating in some state institution, to dissolve for lack of minimal efforts at human interaction. Along with the theories nestled under the umbrella of "externalism" comes a corresponding obligation to be agents of intersubjectivity to our fellow humans suffering from dementia.

### C. *The Need to Combat Self-Fulfilling Dynamics*

Debunking the myth of the empty shell is not sufficient because real-life self-fulfilling dynamics—"positioning and labeling" and "malignant psychology"—force dementia sufferers into the role of the empty shell.

Interactive labels affect both the labeler and the one labeled.<sup>156</sup> When a person is labeled as demented, others "position" themselves in such a way that the demented person is seen as lesser, marginalized.<sup>157</sup> We all take positions as to others and to ourselves relative to that other.<sup>158</sup> The "[p]ositions help to define, strengthen, or weaken [the other] person's moral and personal attributes and help to create story-lines about [the person]."<sup>159</sup>

While most of us can counter false, negative positioning—e.g., I trip, and you position me as "clumsy"; I retort that there was a huge crack in the sidewalk, pointing it out for all to see—because of their

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<sup>155</sup> *Id.* at 167.

A decent society will organize public space, public education, and other relevant areas of public policy to support such lives [i.e., the lives of the mentally and physically disabled] and fully include them, giving the caregivers all the capabilities on our list, and the disabled as many of them, and as fully, as is possible.

*Id.* at 222.

<sup>156</sup> See Hughes et al., *supra* note 15, at 3.

<sup>157</sup> See Snyder, *supra* note 66, at 271.

<sup>158</sup> See Steven R. Sabat, *Mind, Meaning, and Personhood in Dementia: The Effects of Positioning*, in *DEMENTIA*, *supra* note 2, at 287, 289.

<sup>159</sup> *Id.*



language deficits, a person with dementia cannot easily counteract false positioning.<sup>160</sup> The label of “patient”<sup>161</sup> will all but assure that the demented individual will be equated with the disease, and that all behavior will be attributed to the disease,<sup>162</sup> and not with the institutional treatment or caregiver assumptions about the demented person’s capacities.

Thus, if dementia is detached from the social and interactive and seen only within the lens of neuropathology, the person suffering from dementia will be perceived as solely comprised of disease and deficits.<sup>163</sup> All the “troublesome” language and behavior will be perceived as symptoms of the disease, irrational and meaningless as to content, and therefore, appropriately ignored socially and instead treated medically.<sup>164</sup>

In fact, even very experienced, compassionate Alzheimer’s caregivers often tend to see the person’s troublesome behavior as part of the disease and not as part of the person.<sup>165</sup> There is no doubt in my mind from watching my mother’s decline that there was something good about her experienced caregivers’ ability to just laugh when the always dignified mother of my childhood would mouth, “Get over here fat ass.” But there is an equally troubling, if not harmful, *aspect* to this approach if it is the invariable prism

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A position in a conversation, then, is a metaphorical concept through reference to which a person’s ‘moral’ and personal attributes as a speaker are compendiously collected. One can position oneself or be positioned as e.g., powerful or powerless, confident or apologetic, dominant or submissive, definitive or tentative, authorized or unauthorized, and so on. A ‘position’ can be specified by reference to how a speaker’s contributions are hearable with respect to these and other polarities of character, and sometimes even of role. Positioned as dependent, one’s cry of pain is hearable as a plea for help. But positioned as dominant, a similar cry can be heard as a protest or even as a reprimand. It can easily be seen that the social force of an action and the position of the actor and interactors mutually determine one another.

L. van Lagenhove & R. Harré, *Introducing Positioning Theory*, in *POSITIONING THEORY: MORAL CONTEXTS OF INTENTIONAL ACTION*, 14, 17 (Ron Harré & Luk van Lagenhove eds., 1999).

<sup>160</sup> See Sabat, *supra* note 158, at 289. See generally van Lagenhove & Harré *supra* note 159, at 20.

<sup>161</sup> See Sabat, *supra* note 158, at 297; Snyder, *supra* note 66, at 271.

<sup>162</sup> See Sabat, *supra* note 158, at 287, 289.

<sup>163</sup> Murna Downs et al., *Understandings of Dementia: Explanatory Models and Their Implications for the Person with Dementia and Therapeutic Effort*, in *DEMENTIA*, *supra* note 2, at 235, 239–44 (discussing the “medical model” approach to dementia).

<sup>164</sup> See Downs et al., *supra* note 163, at 240.

<sup>165</sup> See Oppenheimer, *supra* note 67, at 202.

through which the demented are viewed. This dark perspective has been labeled “malignant social psychology.”<sup>166</sup>

What is characterized as “challenging” or “troublesome” behavior, far from being no more than meaningless external manifestations of the disease, is often an attempt to communicate needs and feelings.<sup>167</sup> As such the “paranoid symptomology” that the individual is accusing caregivers of stealing belongings may be more than a consequence of serious memory loss. Rather, the person may be communicating the image of one from whom everything is being taken away, and who is therefore unreasonably wary about the fate of remaining possessions.<sup>168</sup> This view may or may not be a bit far-fetched. But there is nothing far-fetched in thinking that people’s challenging behavior at mealtimes may be an attempt to communicate some genuine feeling about the food, where they are seated and with whom, their level of hunger, the time of meals in the facility, etc.

Herein lies the malignancy. Demented persons experience the breakdown of communication with others, increasingly feeling “shut out.”<sup>169</sup> Nevertheless, they communicate on many levels besides regular language.<sup>170</sup> If attempts at communication lead to negative experiences (shame, anger, being ignored) because the caregiver perceived these attempts to be just meaningless symptoms of the disease, demented persons may further withdraw and cease attempting to communicate.<sup>171</sup> The vicious cycle of decline follows with the person increasingly losing the capacity to make meaning.<sup>172</sup> If one treats the person as if he or she makes no sense, he or she will not communicate. If one does the opposite, one may begin to understand.<sup>173</sup>

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<sup>166</sup> See TOM KITWOOD, *DEMENTIA RECONSIDERED: THE PERSON COMES FIRST* 46–47 (1997).

<sup>167</sup> See Downs et al., *supra* note 163, at 245.

<sup>168</sup> See Snyder, *supra* note 66, at 265.

<sup>169</sup> *Id.* at 259, 261.

<sup>170</sup> See, e.g., McMillan, *supra* note 143, at 67–68; Snyder, *supra* note 66, at 260 (demented persons communicate through body gestures, voice tones, facial expression, and mime); Widdershoven & Berghmans, *supra* note 126, at 179.

<sup>171</sup> See Snyder, *supra* note 66, at 261.

<sup>172</sup> See Widdershoven & Berghmans, *supra* note 126, at 179, 187.

<sup>173</sup> See Snyder, *supra* note 66, at 261; see also Guy A.M. Widdershoven & Ron L.P. Berghmans, *Advance Directives in Dementia Care: From Instructions to Instruments*, 44 *PATIENT EDUC. & COUNSELING* 179, 184 (2001) (stating that demented persons can communicate, but communication takes more time and patience than most are willing to give).

In her first residence, my mother confronted malignant positioning firsthand. We received a call from the residence. “Your Mom threw a lamp at the nursing desk. Come down!” Sure enough, there was the smashed lamp at the base of the central nursing station.

Mom was in her room, looking a bit sheepish. “Mom, did you throw a lamp?” Smile, nod. “Mom, did you do that deliberately?” Smile, nod. “Mom, why did you deliberately throw a lamp at the nursing desk?” Mom was having greater and greater difficulty expressing herself. The word she was groping for would almost be there and then float away from her, and she would grasp for the closest categorical approximation that she would associate in her mind for the real word she was looking for. Thus, her attempt to say “the attendant” may come out as “the work thing.” Much decoding was necessary. But, slowly, we got the story. An attendant came to shower Mom several times a week. Mom’s skin was very sensitive, and the spray of water from the shower was uncomfortable for her. This particular 180-pound attendant, however, could not have cared less what this babbling old woman was saying. She would grab Mom, force her into the shower, and roughly scrub her hair, really hurting and frightening Mom. Think about it from Mom’s side. A huge thug had a key to just walk into her home at will and beat her up. Mom was alone, defenseless. Her home, rather than providing a sense of security, made her vulnerable and available to this demon. What could Mom do? She went to complain at the nursing desk. She stood there, and they ignored her. So she picked up the lamp on the counter and threw it. “Then they paid attention to me.” Smile.

Even at this supposedly posh residence, the elderly were being abused. They were just as vulnerable, and the low-skill, low-pay, minimally educated attendants differed little from those in any other facility dealing with the elderly. Her attempt to report that abuse, however, was interpreted solely through the lens of neuropathology. Due to malignant positioning, it was unimaginable to the staff that this crazy lamp-hurling woman may have come to the nursing desk with a legitimate complaint.

Consistent with the concept of “malignant social psychology,” studies show that demented patient’s neurological functioning is damaged by impoverished environments<sup>174</sup> and enhanced by rich

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<sup>174</sup> See Downs et al., *supra* note 163, at 245.

ones,<sup>175</sup> including dementia support groups.<sup>176</sup> Similar inferences are derived from studies of “excess disability” in dementia sufferers.<sup>177</sup> Excess disability refers to persons who showed far more impairment than one would expect from the actual damage to the brain found during an autopsy.<sup>178</sup> Social environment seems a likely suspect to account for the disparity.

Old age psychiatrists daily see patients who experience some threat to their autonomy, and a minority of our patients, at some point in their lives, can scarcely be said to make autonomous decisions at all. Yet we see that these patients, for all their impaired autonomy, play an immensely significant part in the lives of the people who are connected to them. They are participants in relationships that can be joyful and rewarding; or troublesome, full of pain and guilt; relationships deeply rooted in the past, or fresh encounters between a new carer and the person needing care. *It is the emotional context of these relationships (or their absence) that determine how much the person flourishes or withers, how much his potential for affection, enjoyment, humour, and the vivid communication of feeling, are stifled or expressed.*<sup>179</sup>

Having shattered the myth of the empty shell, we can now look squarely at the numerous impediments to constructing a regulatory regime for PAS and dementia. As the following will demonstrate, those impediments will prove insurmountable.

### III

#### THE IMPOSSIBILITY OF CREATING AN ACCEPTABLE LEGAL REGIME TO REGULATE PAS AND DEMENTIA

##### A. *The Paradox of Dementia and Consent to Physician-Assisted Suicide*

When considering PAS and, for example, terminal cancer, the issue of ensuring that the decision to end one's life was the result of a true

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<sup>175</sup> For a discussion of techniques for improving communication, see BAYLES & TOMOEDA, *supra* note 1, at 195–202. But see Stephen G. Post, *Alzheimer Disease and Physician-Assisted Suicide*, 7 ALZHEIMER DISEASE & ASSOCIATED DISORDERS 65, 67 (1993) (expressing concern that if the law permits PAS for dementia, then society will cease trying to develop ways to improve treatment of demented persons).

<sup>176</sup> BAYLES & TOMOEDA, *supra* note 1, at 262–64.

<sup>177</sup> See *id.* at 125, 131; Brody et al., *supra* note 91, at 125, 131.

<sup>178</sup> See MACE & RABINS, *supra* note 18, at 293.

<sup>179</sup> Catherine Oppenheimer, *Ethics in Old Age Psychiatry*, in PSYCHIATRIC ETHICS 317, 321 (Sidney Bloch et al. eds., 3d. ed. 1999) (emphasis added); see also Hughes et al., *supra* note 15, at 25.

autonomous choice is not unproblematic. Concerns about possible coercion by family<sup>180</sup> or coercion embedded within the patient-physician interchange<sup>181</sup> are prevalent. Even more so is the question of the chooser's mental competency,<sup>182</sup> as suicidal ideation in general

<sup>180</sup> See Leon R. Kass, "I Will Give No Deadly Drug": Why Doctors Must Not Kill, in THE CASE AGAINST ASSISTED SUICIDE, *supra* note 8, at 17, 19.

This is a recurrent and real concern, which appears anywhere there is a discussion of assisted suicide. Very sick people are extremely vulnerable. They are exhausted from fighting the disease and pain and often depressed by what is happening to them. In this state, they are often ambivalent about suicide, changing their minds back and forth in relatively short periods of time. America has such a strong culture of independence and self-reliance that dependence becomes a source of shame. And very sick people are extremely dependent; yet, ironically, this culture of self-reliance leads them to distance themselves from others at the very time they most need others. I know it bothered my father, though he never said so. They are also extremely sensitive about being a financial and emotional burden on their loved ones. Under these circumstances, they are susceptible to pressure from those close to them conveying the message that it is time for them to die, especially since they might already feel they have a "duty" to die.

MITCHELL, *supra* note 5, at 54–55 (footnotes omitted); see also *id.* at 54–55, nn.26–34.

<sup>181</sup> See J.P. Bishop, *Framing Euthanasia*, 32 J. MED. ETHICS 225, 227 (2006) (using experience with Do Not Resuscitate orders to demonstrate how doctors can completely influence their patients' choices by the specific word choices the physicians use in presenting options); see also RAPHAEL COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS: THE POLICY AND PRACTICE OF MERCY KILLING 97–98 (2004) (observing that by presenting the topic of euthanasia as a just "medical" option, doctors can influence their patients' decisions); Callahan & White, *supra* note 3, at 28 (addressing the difficulty of assessing the adequacy of a particular patient's consent for PAS because the patient will be dead).

<sup>182</sup> See Malcolm Parker, *End Games: Euthanasia Under Interminable Scrutiny*, 19 BIOETHICS 523, 526 (2005) (Australian researchers claim a new psychiatric diagnosis, Demoralization Syndrome (DS), rules out the possibility of a rational suicide, finding the "desire to die being symptomatic of the detectable pathological condition."); Mark D. Sullivan et al., *Should Psychiatrists Serve as Gatekeepers for Physician-Assisted Suicide?*, HASTINGS CENTER REP., July–Aug. 1998, at 24, 25 (explaining that the modern medical model concluded that suicide is never the choice of a rational agent, but rather a symptom of mental illness); see also David M. Clarke & David W. Kissane, *Demoralization: Its Phenomenology and Importance*, 36 AUST. & N.Z. J. PSYCHIATRY 733 (2002); Lillie & Werth, Jr., *supra* note 14, at 2 ("Let me be clear here: I do not agree with the concept of rational suicide, especially as applied to people with disabilities, primarily because of social and cultural concerns . . ."). But see HUMPHRY & CLEMENT, *supra* note 11, at 76 (explaining that suicide can be a totally rational response to a particular situation); James G. Adams, *Life or Death: Physician-Assisted Suicide and Emergency Medicine*, 3 ACAD. EMERGENCY MED. 909, 909 (1996) (finding sixty-one percent of primary care physicians believe that suicide can be rational); Kyriaki Mystakidou et al., *The Evolution of Euthanasia and Its Perceptions in Greek Culture and Civilization*, 48 PERSP. BIOLOGY & MED. 95, 96 (2005) ("Though suicide is generally viewed to be a pathological state of mind, most often linked to depression, some professionals hypothesize that suicide in some circumstances can be quite rational."); Parker, *supra*, at 527 (seeing the fact that

is strongly correlated with mental illness,<sup>183</sup> and not surprisingly, those with terminal illnesses seeking PAS are often depressed.<sup>184</sup>

Allowing PAS for dementia surely raises all these concerns. It also raises what I term a “Catch-22” problem.<sup>185</sup> Autonomous decision making presupposes that two conditions exist for choosers: (1) they have full information<sup>186</sup> and (2) they are competent.<sup>187</sup> It is not difficult to imagine someone with cancer who has been diagnosed with having six months to live as possessing both the knowledge (i.e., the diagnosis and the likely course of disease) and the mental capacity to make an autonomous choice to seek PAS. But dementia is different.

Before the onset of the dementia, the individual plainly has the capacity to make a meaningful choice. But does the person have anything like full information? It is correct, as proponents of complete autonomy assert, that all choices we make about matters that will take place in the future involve things we do not know;<sup>188</sup> none of us can see into the future. However, this situation seems qualitatively different. I choose a mate to marry, expend large amounts of money on education to prepare for a career, and book cross-Atlantic flights on nonrefundable tickets. The reality is that

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those refusing to accept that someone can rationally choose PAS but not making the same claim about the rationality of those who refuse life-sustaining treatment “suggests that a particular moral view about assisted dying is helping to demonstrate the existence of the clinical disorder [undermining the capacity for rational suicide]”).

<sup>183</sup> KAY REDFIELD JAMISON, *NIGHT FALLS FAST: UNDERSTANDING SUICIDE* (1999); *SUICIDE* (Robert Emmet Long ed., H.W. Wilson Co. 1995) (reprinting various magazine articles).

<sup>184</sup> See N. Gregory Hamilton & Catherine A. Hamilton, *Competing Paradigms of Response to Assisted Suicide Requests in Oregon*, 162 AM. J. PSYCHIATRY 1060, 1060 (2005) (“Although physical illness may be a precipitating cause of despair, these patients usually suffer from treatable depression and are always ambivalent about their desire for death.”). But see Chochinov & Schwartz, *supra* note 8, at 268 (explaining that the correlation between suicidal ideation and hopelessness is greater than that between suicidal ideation and depression); Sullivan et al., *supra* note 182, at 24, 28 (showing that the terminally ill seeking PAS are not more likely to be depressed).

<sup>185</sup> The *Oxford English Dictionary* defines “Catch-22” as:

[A] supposed law or regulation containing provisions which are mutually frustrating . . . ; a set of circumstances in which one requirement, etc., is dependent upon . . . the first. Freq. *attrib.*, esp. as *Catch-22 situation*. [f. a paradoxical rule postulated in the novel *Catch-22* . . . , by Joseph Heller. . . .]

2 THE OXFORD ENGLISH DICTIONARY 973 (Clarendon Press 2d ed. 1989).

<sup>186</sup> See Todd Goldberg, *A Doctor Looks at Assisted Suicide*, 1 NAVIGATOR 35 (1998).

<sup>187</sup> See SOMERVILLE, *supra* note 7, at 317–20.

<sup>188</sup> See Widdershoven & Berghmans, *supra* note 126, at 181–82.

none of these choices may turn out as I envisioned.<sup>189</sup> Yet in the future, my reality will still be my own, perceived through the mind with which I have become familiar. The experience may have “changed” me in some respects—from open to cautious, optimistic to cynical, sloppy to careful about details, happy to sad, filled with love to filled with anger, or vice versa—but the basic way my mind functions as a mind will not have changed. I will just have incorporated an additional or modified set of conceptual schemata into my semantic memory.

With more than mild dementia this simply will not be true. Thinking about being demented is not analogous to thinking about any other future prospect. In this situation, you are literally considering how you would think if your mechanisms for thinking and communicating were radically different. I do not think that is really possible. I can talk to others I respect about the realities of marriage or a career as a graphic artist,<sup>190</sup> but I do not see how I can do that with someone with dementia. It is not that they cannot tell their stories—they can.<sup>191</sup> It is just that I can only look at their stories through an undemented mind. Though I can feel empathy toward and understand in a narrative sense what those with dementia are saying when relating their experiences, I cannot really comprehend what it would be like to have a radically differently functioning mind when my only tool of comprehension is my ordinarily functioning mind. I have an imagination, and actors and actresses are certainly capable of convincingly “playing” a demented person, such as in the movie *Iris*.<sup>192</sup> These performances of the imagination are nevertheless effectively external. Dementia is the object of the audience’s nondemented subjectivity. I can imagine the world of the demented through my eyes but not through their brains.

Less philosophically, dementia sufferers are no more alike than those without dementia. We are all unique individuals, demented or not. Individuals thus experience dementia differently,<sup>193</sup> both due to

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<sup>189</sup> See Daniel Gilbert, *Foreword* to STUMBLING ON HAPPINESS, *supra* note 10, at xvi–xvii.

<sup>190</sup> See GILBERT, *supra* note 10, at 251–56.

<sup>191</sup> See *supra* note 65 and accompanying text. But see Phinney, *supra* note 95, at 340 (explaining that those with mild to moderate dementia are unaware of or deny memory deficits).

<sup>192</sup> IRIS (Miramax Films 2001) (telling the story of Irish novelist Iris Murdoch as she suffered from Alzheimer’s disease).

<sup>193</sup> See MACE & RABINS, *supra* note 18, at 13.

the persona they are and to the specific area and magnitude of organic damage to the brain.<sup>194</sup> Additionally, no matter how we position ourselves on the philosophical issue of whether the “person” may or may not “survive” when suffering serious dementia, it is true that some people with dementia present dramatic personality changes.<sup>195</sup>

On the other hand, if we insist that individuals have full information before choosing PAS, we run into another set of problems. Once an individual is in the middle stages of Alzheimer’s, he or she has a pretty good sense of what it may be like to be demented. The individual’s competence to consent is quite another issue.<sup>196</sup> Is it enough if the demented person says “I wish I was dead?” This might just be a metaphorical way of expressing sadness or even (treatable) depression. Even if meant at the moment, there is no reason to believe the desire will persist. All of us have bad days, and my experience visiting my demented mom in her Alzheimer’s residence made it clear to me that so do the demented. This is particularly problematic because the person’s feelings could be the result of the care they are receiving, and thus a result of “malignant psychology.”

Moreover, all current and proposed statutes permitting PAS in terminal illness require persistency of the request<sup>197</sup> and consultation with physicians (and mental health professionals if indicated). But a person with middle- or late-stage dementia may not be able to understand the information provided in a consultation,<sup>198</sup> and have great difficulty retaining or retrieving it from memory after the consultations to “think it over.” Also, because demented individuals have lost their values framework in their semantic memory,<sup>199</sup> they

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<sup>194</sup> “The profiles of cognitive-communicative deficits of individuals with dementia reflect the distribution of neuropathology associated with their disease.” BAYLES & TOMOEDA, *supra* note 1, at 36.

<sup>195</sup> See MACE & RABINS, *supra* note 18, at 290.

<sup>196</sup> See BAYLES & TOMOEDA, *supra* note 1, at 66 (stating that the demented person experiences diminished comprehension of both written and spoken word). Interestingly, a similar conundrum has been explored in the context of cult programming. See Richard Delgado, *Religious Totalism: Gentle and Ungentle Persuasion Under the First Amendment*, 51 S. CAL. L. REV. 1, 54–55 (1977) (positing that in some settings, such as religious brainwashing in cults, an individual begins with full capacity but lacks knowledge; while later, when the individual acquires more knowledge, the capacity has suffered diminution).

<sup>197</sup> Existing PAS regimes require persistency in requesting PAS. See MITCHELL, *supra* note 5, at 77–78 (The Netherlands); *id.* at 90 (Oregon).

<sup>198</sup> See Widdershoven & Berghmans, *supra* note 126, at 180.

<sup>199</sup> See *id.*



will likely be unable to evaluate the information discussed, even if they can somehow retain it in memory. This is not intended to demean the dementia sufferer's capacity for understanding and ability to make meaning. Realistically, however, the option of PAS would be an intellectually, emotionally, psychologically, spiritually, and existentially difficult conversation for any of us at our best. The dementia sufferer is not at his or her best.

What about setting the line at something comparable to early-stage Alzheimer's? Surely at that point, the person has a fairly vivid picture of what lies in store for them while still retaining their cognitive decision-making capacities. This superficially seems akin to the "bright line" of "terminal illness with less than six months to live." In fact, early-stage Alzheimer's has diagnostic criteria including specific ranges of results from tests. Granted, this may be the period of time when the person is most frightened,<sup>200</sup> aware of being both in the world that was (and in which participation is still somewhat possible) and the world that awaits (and into which entrance is inevitable). However, this is the kind of decision for which there is really no ideal time.

If we accepted this "early Alzheimer's" line,<sup>201</sup> we would still have to evaluate what this person could decide. For a number of reasons, I don't think we would contemplate "kill me tomorrow." This is not like the "six months to live" metaphor. No one really knows how to

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<sup>200</sup> See MACE & RABINS, *supra* note 18, at 122.

<sup>201</sup> I recognize that my construction of the semidemented state (where, on the one hand, the person has some firsthand experience with dementia while, on the other, the person retains sufficient competence to make an autonomous choice) will likely completely lose its neat analytic compass in real-life application. People often engage in denial or obfuscating behavior at this stage. Thus, it is very common for people exhibiting early signs of dementia to refuse to admit or acknowledge the condition, while becoming angry when the possibility is suggested. MARKUT & CRANE, *supra* note 18, at 21. *But see id.* at 23 (indicating some feel better because they know it is a disease and they are not "stupid"). Conversely, families understandably are often equally reluctant to acknowledge the deteriorating mental status of a loved one, especially since some memory loss is part of the normal aging process. *See id.* at 4–5; BAYLES & TOMOEDA, *supra* note 1, at 47–48. Will early dementia sufferers want to sit down and discuss an advanced directive for a condition they (and their families) are inclined to refuse to even acknowledge?

My family really did not face the fact that mom had dementia. We attributed her behavior to everything but dementia. By the time we acknowledged her condition, she was well past early-stage Alzheimer's.

How common will this be for others, especially considering the difficulty of assessing the cognitive location of the person at any particular time along dementia's journey? Plainly, it will be absurd to think of these stages as bright-lined, like crossing a national border. It will be a combination of medicine, intuition, and storytelling about and with the person.

calculate at which point someone with dementia actually is “terminal.”<sup>202</sup> A demented person can live for a decade or more after diagnosis.<sup>203</sup> Will we let someone have medical assistance in dying because of the (perhaps justified) fear of what the future will hold, though that future may not arise for many years? The person almost certainly will worsen over time, but it will be in increments. In those years, treatments, even a cure, could become available. In fact, some treatments currently exist,<sup>204</sup> and with the threat of dementia to the relatively affluent population bulge we call the baby boomers, research and development in the area is only likely to increase. Additionally, our reticence to allow PAS on the basis of the fear of the future is understandable when one of our greatest overall concerns is cabinining the scope of its availability.<sup>205</sup>

*B. The Living Will as Delegation of Unrestrained Discretion over the Life and Death of the Dementia Sufferer*

What will we allow the dementia sufferer to decide? We might consider, with the persistence of request and consultation requirements analogous to those in PAS regimes for terminal illnesses, permitting the mildly demented person to author a living will or advanced directive laying out the terms under which the dementia must have progressed for the person to be euthanized (because the sufferer will not be able to understand at that point the

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<sup>202</sup> MARKUT & CRANE, *supra* note 18, at 206.

<sup>203</sup> For example, the middle stage of Alzheimer’s can last from four to ten years. BAYLES & TOMOEDA, *supra* note 1, at 65.

<sup>204</sup> See source cited *supra* note 20.

<sup>205</sup> The PAS debate is infused with concerns that once permitted we will not be capable of cabinining its application:

Also, it would be difficult to limit suffering to pure physical pain. . . . Suffering is far more complex. It is a mix of the physical, emotional, existential, and psychological. Even suffering from physical pain has emotional and psychological elements. . . . In fact, most terminal patients who seek assisted suicide do not do so because of physical pain. . . . They are worn down from the breakdown of their bodily functions, their inability to care for themselves, inability to be part of a social community, the emotional and financial burden they feel they are to their loved ones, and their general sense of hopelessness. . . . Of course, once law cuts the mooring from physical pain, how can it ignore unremitting psychological suffering? Does a broken leg cause as much physical (let alone emotional) pain as having a spouse suddenly announce that she is leaving and wants a divorce?

Mitchell, *supra* note 7, at 61–62 (footnotes omitted); see also MITCHELL, *supra* note 5, at 18.

purpose of taking certain pills, or may have even forgotten how to swallow,<sup>206</sup> so PAS is not really a viable choice). As with everything else in this area, a living will for medical termination of the life of a demented person will not be unproblematic.

Practical issues spring forth about drafting, interpretation, and implementation. Philosophical issues arise about privileging the semicompetent over the incompetent self. Social issues emerge about cultural coercion for the diagnosed demented to execute living wills requesting euthanasia. Each of these problems merits careful consideration.

Initially, there will be real challenges in drafting. What are the terms or criteria that will trigger the medical termination of life? You cannot use results on tests because they do not necessarily reflect the extent of impairment, often overstating the deficits when compared to the actual functioning of the individual.<sup>207</sup> Perhaps terms meaningful to the individual's narrative will suffice: an inability to recognize any immediate family and friends or a lack of orientation to self (e.g., not responding to the person's own name). While this may initially seem clear, it is not as simple and straightforward. The application of advance directives is not considered in some abstracted space. Like treatment, the decision always takes place in a concrete situation and requires interpretation.<sup>208</sup> "When can the doctor be sure that the patient no longer recognizes family and friends? Is this when their names have been forgotten? Or when [patients] no longer seem to regard them as people who mean something to them in some way? How should we decide the latter?"<sup>209</sup>

Even as to the sufferer not responding to her name, does the person really understand who the name refers to but, because of damage to certain segments of her brain, cannot express that understanding? Or does the person fully understand but is angry at some treatment (e.g., ignored, spoken about in very insulting terms right in front of the

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<sup>206</sup> See *supra* notes 91–92 and accompanying text.

<sup>207</sup> See Hughes et al., *supra* note 15, at 12, 14; Snyder, *supra* note 66, at 260.

<sup>208</sup> See Widdershoven & Berghmans, *supra* note 126, at 189; Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 L. MED. & HEALTH CARE 234, 237 (1989); J.J.M. van Delden, *The Unfeasibility of Requests for Euthanasia in Advance Directives*, 30 J. MED. ETHICS 447, 448–49 (2004).

<sup>209</sup> Widdershoven & Berghmans, *supra* note 126, at 189.

person as if not in existence)?<sup>210</sup> How many times does the sufferer need to fail to respond to a name before PAS takes its course and the person is killed? Must the person be given a warning first in the tradition of a warning shot? What if the sufferer cannot understand the warning due to cognitive deficits, though understanding the name? The interpretive point is clear.

The philosophical issue of *privileging* opposes a competent self executing the directive and an incompetent self potentially being executed by the terms of that same directive. I have posited a less than fully competent person, but competent enough—a sort of competent-light. The fact that someone gets lost on walks, forgets to take messages, and increasingly struggles to find precisely descriptive words does not mean, however, there is a lack of capacity to understand the nature and consequence of a life or death decision. I do not believe that positing a semicompetent author of a living will changes the basic philosophical question about the legitimacy of privileging the wishes of the semicompetent self over the incompetent self.

Proponents of full autonomy argue the wishes of the autonomous self (or semiautonomous in the case I am positing) are the only wishes that matter as the seriously demented person cannot make autonomous choices.<sup>211</sup> But this position presents, albeit in a different form, the same set of assumptions underlying Lockean philosophy and cognitive psychology—that only the self-enclosed, self-conscious product of the rational mind counts.

If the semicompetent and the demented persons were literally different “selves,” then the advanced directive would, in effect, be a contract for murder by hire. But that characterization of literally different selves does not reflect in any way how I, or anyone I know, see the world. In the end, Mom was very confused and generally not accessible to those around her, but she was unequivocally still Mom. Still, I have no doubt that the semicompetent self and the incompetent self might well have very different interests.<sup>212</sup> They might even be

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<sup>210</sup> See Sabat, *supra* note 158, at 290–91. For another scholar who believes that the demented should be respected for who they are now, see John A. Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 GA. L. REV. 1139, 1166–67 (1991); John A. Robertson, *Assessing Quality of Life: A Response to Professor Kamisar*, 25 GA. L. REV. 1243, 1245, 1248 (1991).

<sup>211</sup> See Dresser & Robertson, *supra* note 208, at 236; Widdershoven & Berghmans, *supra* note 126, at 181–82.

<sup>212</sup> See Dresser & Robertson, *supra* note 208, at 236.

more dissimilar than those of the sixteen-year-old self and the fifty-five-year-old version.

Entering into this philosophical fray, Professor Ronald Dworkin<sup>213</sup> would lay down a card on the table that he contends allows the past self to trump the present. He names this card “precedential autonomy.”<sup>214</sup> The previously expressed desire of the competent (or semicompetent in my conception) self trumps because it is an expression of who the person really is. This person has tried to create a coherent life, a life with integrity. It is their autonomous decision as to how they want that life to play out (“I am someone who is capable, grounded, realistic. I am not someone who is helplessly deluded”),<sup>215</sup> and the decision provides a sense of comfort to them to believe that

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When people become incompetent and seriously ill, however, their interests may radically change. With their reduced mental and physical capacities, what was once of extreme importance to them no longer matters, while things that were previously of little moment assume much greater significance. An existence that seems demeaning and unacceptable to the competent person may still be of value to the incompetent patient, whose abilities, desires and interests have so greatly narrowed.

It is difficult, if not impossible, for competent individuals to predict their interests in future treatment situations when they are incompetent because their needs and interests will have so radically changed. As a result, the directives they issue for future situations of incompetency, though they reflect their current needs and interests, may have little relevance to their needs and interests once they become incompetent. Indeed, their advance directives may even be detrimental to their interests once in that state.

*Id.*; see also Tony Hope, *Advance Directives About Medical Treatment: Making Up One's Mind While One Still Has a Mind*, 304 BRIT. MED. J. 398, 398 (1992).

<sup>213</sup> See generally DWORKIN, *supra* note 18.

<sup>214</sup> *Id.* at 224, 226, 232. For an excellent argument that Dworkin defines autonomy too narrowly, so as to incorrectly exclude the demented, see Seana Valentine Shiffrin, *Autonomy, Beneficence, and the Permanently Demented*, in DWORKIN AND HIS CRITICS WITH REPLIES BY DWORKIN 195, 202–03 (Justine Burley ed., 2004).

<sup>215</sup> See DWORKIN, *supra* note 18, at 227–28. On the other hand, the healthy have trouble envisioning anything positive in the life of the ill:

The tendency that causes us to overestimate the happiness of Californians also causes us to underestimate the happiness of people with chronic illnesses or disabilities. . . . For example, when sighted people imagine being blind, they seem to forget that blindness is not a full-time job. Blind people can't see, but they do most of the things that sighted people do—they go on picnics, pay their taxes, listen to music, get stuck in traffic—and thus they are just as happy as sighted people are. They can't do *everything* sighted people can do, . . . and thus blind and sighted lives are not identical. But whatever a blind person's life is like, it is about much more than blindness. And yet, when sighted people imagine being blind, they fail to imagine all the other things that such a life might be about, hence they mispredict how satisfying such a life can be.

GILBERT, *supra* note 10, at 114–15.

this advanced directive will ensure that the ending of their life story will be consistent with who they “really are.”

The core premise underlying Dworkin’s notion of precedential autonomy is that the autonomous person chooses the “critical interests”<sup>216</sup> (central elements of our lives) that define the life story of who that person is. It violates that autonomy if a nonrational (and thereby nonautonomous) version subsequently alters that story.<sup>217</sup>

I disagree for two reasons. First, the notion of autonomy as a means of creating a coherent “story” of ourselves to be left behind, etched in the memory of history, is a false one mired in illusion. Every philosophical perspective on narrative as the construct establishing identity was oriented around the fundamental conception that, though we are active participants in the creation of a self-narrative, the story is in no sense ours alone. Limited and circumscribed by social conventions, given meaning through interaction with others, and being in part a function of how others choose to see and “position” us, the notion that we can autonomously author our story belies the reality that our stories are created of and in the world, and that we have scant control over the external world.<sup>218</sup>

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<sup>216</sup> See DWORKIN, *supra* note 18, at 201–07. For an excellent summary of Dworkin’s position, see Shiffrin, *supra* note 214, at 197, which states:

Dworkin maintains that a demented person *qua* demented person lacks a critical interest in continuing to live. Demented people may have experiential interests in their lives. They may have good or bad experiences within them; they can, for instance, enjoy comfort and reassurance or feel pain and fear (p. 227). They cannot, however, take a view of their lives as a whole, and hence they cannot form opinions about their critical interests. That is, they cannot assess what renders their lives a success or a failure and what, within a life, pays proper heed to the sanctity of life (pp. 201, 230). Moreover, Dworkin thinks that not only are demented people incapable of understanding what is in their critical interests, they cannot do anything to further their critical interests. He claims they are incapable of the acts and attachments that give life value. Value, he notes, “cannot be poured into a life from the outside; it must be generated by the person whose life it is, and this is no longer possible for [the demented person]” (p. 230).

<sup>217</sup> See DWORKIN, *supra* note 18, at 227–28; Widdershoven & Berghmans, *supra* note 126, at 181. But see Thomas May, *Slavery, Commitment, and Choice: Do Advance Directives Reflect Autonomy?*, 8 CAMBRIDGE Q. HEALTH CARE ETHICS 358, 358 (1999) (arguing that an advance directive that relinquishes future judgment is inconsistent with autonomy because it is the “ability to re-evaluate one’s commitment to the second order strategy [i.e., a document such as an advance directive requiring PAS if one becomes demented] that is key for the strategy’s consistency with autonomy”).

<sup>218</sup> See *supra* notes 38, 39, 40 and accompanying text.

Further, there is no reason why the chapters of our stories cannot be rewritten, altered, or added by a now “mad” author.<sup>219</sup>

Second, one may fairly ask why the cognitive is consistently privileged over the affective in constructs of personal identity.<sup>220</sup> Perhaps on a Darwinian level one may feel cognitive capacities are central to our survival, yet equally central would seem to be our instincts and intuition about things in the world. “Emotional intelligence” is not some fringe notion. Rather, it is accepted as a capability that is necessary for success in our modern workplace.<sup>221</sup>

Also, language itself does not find its sole function in rational dialogue. Of course language can include a “representational dimension” in which one communicates substantive information to another, but this is not necessarily so.<sup>222</sup> Language can be purely “expressive,” containing no representational dimension and instead serving as a device to establish “the kind of rapport which is peculiar to us linguistic animals.”<sup>223</sup> From the mere fact we speak, there is a connection. That connection exists whether speech takes the form of a completely unfamiliar foreign language or the seemingly unconnected ramblings of some demented individual. Even when my mother could not express a single coherent phrase, there were times when she would hold my hands, utter some unintelligible string of phrases, and smile, and “the meaning” she expressed and connection I experienced was immeasurably more significant than if she had given an articulate analysis of the history and current appropriateness of the electoral college.

But my objections go far beyond parting with moral philosophers. They reside in the specter of a future world in which staggering numbers of old, demented people are put to death. If we accept precedential autonomy, we will come back to problems of

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<sup>219</sup> In questioning Professor Dworkin’s concept of a coherent life narrative, Rebecca Dresser raises a similar thought: Can one’s life story have a “surprise ending”? Rebecca Dresser, *Dworkin on Dementia: Elegant Theory, Questionable Policy*, HASTINGS CENTER REP., Nov.–Dec. 1995, at 32, 36 (1995).

<sup>220</sup> See Allen & Coleman, *supra* note 143, at 218 (highlighting the value of the “spiritual” nature, which is unrelated to cognition); Post, *supra* note 115, at 227; Widdershoven & Berghmans, *supra* note 126, at 182. In fact, one author terms “hypercognitive” as a form of moral blindness. See Post, *supra* note 115, at 223, 231.

<sup>221</sup> See generally DANIEL COLEMAN, EMOTIONAL INTELLIGENCE (2006); GERALD MATTHEWS ET AL., EMOTIONAL INTELLIGENCE: SCIENCE AND MYTH (2002).

<sup>222</sup> See Hughes et al., *supra* note 15, at 22.

<sup>223</sup> *Id.*; see also CHARLES TAYLOR, HUMAN AGENCY AND LANGUAGE: PHILOSOPHICAL PAPERS 248, 260 (1985).

interpretation. That is obvious. What is less obvious is that we inevitably will have created a regime of absolute, life-and-death “interpretive discretion.” My friend’s mother was severely demented and lived in a care facility. She was cheerful, loved to garden throughout her life, and, in the facility, still daily pattered about a small plot of lovely flowers. When my friend, (“Bill”) and his wife of eighteen years (“Sue”) visited, the mother would be very, very pleasant when they came up to her. She also had absolutely no idea who they were. One day she said to Sue, while Bill was standing right there, “Dearie, too bad you didn’t know my son, Bill. He’s been dead quite a while. Never married, too bad. You’d have liked him.”

If my friend’s mom had executed an advance directive, contingent on not knowing close family, then it is fair to say the critical terms were met and mom would now be subject to having a lethal injection after dinner. There is not any possibility, however, that a remotely nonpsychotic health care professional on this planet would kill this delightful woman because of some piece of paper in the file.<sup>224</sup> What would happen is “interpretive discretion.” The likely interpretation would take the form of something like the following. The fact that she talked about her son and marriage, making clear that Bill and Sue would have liked each other, implies that on some level she comprehends the linkage between Bill and Sue. Saying her son is dead, moreover, is likely a reference to her sense that she and her son are lost to each other because of her dementia. And so the interpretation would go.

But what if my friend’s mom was nasty and always seemed unhappy? Would her interaction with her son and daughter-in-law have been similarly interpreted? And what if it was not and that contrary interpretation was in fact incorrect? There will be no appeals for nasty mom, followed by years of habeas corpus petitions making their way first through the state and then the federal system. Unpleasant mom will be dead by nightfall. Of course, the fact that

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<sup>224</sup> I confess to agreeing with Professor Kadish that, in these circumstances, “compassion” trumps autonomy. See Kadish, *supra* note 110, at 876; accord Shiffrin, *supra* note 214, at 210 (“Likewise, it seems barbaric to ignore the experiential interests of people whose lives are filled with simple joys and delight and to cut these lives off short—to kill them—so that the entire life of [the individual who executed the living will] is unsullied by a lingering period of intellectual deterioration and decline.”).

Professor Dworkin responds to this by saying that, while carrying out the living will is necessary to respect autonomy, other moral values would trump in such a situation. Ronald Dworkin, *Reply: Seana Valentine Shiffrin*, in DWORKIN AND HIS CRITICS WITH REPLIES BY DWORKIN, *supra* note 214, at 370, 370.



even unpleasant mom is paying her bills in a high-priced care facility would likely have a strong influence on the interpretive stance of the members of the care facility, although these are not likely to be the people authorized to carry out the actual euthanasia. But what if the family pressures their doctor to invoke the directive (respect for mom's dignity, more money in the—now almost immediate—inheritance)? Again, there will be no check on interpretive discretion so long as everyone (not counting the demented person) agrees on the interpretation. Only in the case of strong disagreement will there be any possibility that courts will get even a whiff of the situation.

Now change venues. We are walking into a dementia ward funded by an HMO or a vast geriatric, dementia facility in a state mental hospital. The patients have little or no money and most no family or outside support. Is there any doubt how the story of unpleasant mom will end?

There is a final sense in which the specter of coercion rises as a very serious issue. I am thinking less about individual family members or physicians, though that certainly could happen. What I find more concerning is the possibility that there will emerge an understanding that would achieve the status of social expectation, even social obligation.<sup>225</sup> The litany will proceed as follows: dementia sufferers use up a significant amount of our society's very limited funds for health care.<sup>226</sup> We have to make difficult decisions, triaging our scarce health care resources. This country has provided you with an extraordinary amount of freedom and a materially comfortable life, which is the envy of most of the world. We are now asking little from you—in fact, almost nothing. Now that you have been diagnosed with dementia, we ask that you fill out and sign this advanced directive form. And when the time comes, it will not be like you are killing yourself. You will not even exist; only an empty shell or a vegetable will mark where you once lived, inhabiting your body and swallowing up scarce health care resources that otherwise would go to treating sick young children or finding a cure for Alzheimer's.

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<sup>225</sup> This sentiment in fact was explicitly and publicly expressed by then Colorado Governor Richard Lamm: "Elderly people who are terminally ill have a 'duty to die and get out of the way' instead of trying to prolong their lives by artificial means." *Gov. Lamm Asserts Elderly, if Very Ill, Have "Duty to Die,"* N.Y. TIMES, Mar. 29, 1984, at A16. *But see* Oppenheimer, *supra* note 179.

<sup>226</sup> *See supra* notes 29, 30.

I am not envisioning that this message will be posted somewhere in every café selling lattes. But within our cultural mind, this “message” could become accepted dogma, particularly if sheer costs conjoin with a cultural belief that the severely demented are effectively dead, that their lives are indistinguishable from cabbages.

*C. Why an Absolute Ban on Using Living Wills to Facilitate Assisted Suicide as a Response to Dementia Is Necessary*

Even given all that has been said, if a relatively small group of baby boomers wished to execute these agreements in order to provide some peace of mind, that would not be problematic.<sup>227</sup> After all, a significant percentage of those prescribed lethal pills in Oregon, one of the few states that allows euthanasia, do not actually take them; the mere existence of the option perhaps permits them to relax.<sup>228</sup> Of course with an advanced directive for PAS, demented persons will not have the ability to change their minds like those who can choose not to take the pills. Rather, they will be relying on the (interpretive) kindness of strangers.

Though I have no personal problem with this notion, there seems an insurmountable policy problem with permitting even these “few baby boomers” to create advanced directives. There are no principled basis or empirical guess (e.g., that only certain types of individuals, small in number, execute such living wills; or that information about the actions of these few would not reach the mass of our media-drenched society) that would ensure these actions would be limited to the few. And, if signing advanced directives becomes a cultural norm, then I have a serious problem because of unfettered “interpretive discretion.” While this may also apply to current living wills, which include “Do Not Resuscitate” provisions, there is a huge difference with dementia. Living wills that permit tubes to be pulled and treatments not to be carried out (e.g., not treating pneumonia when a person is dying of cancer or a ninety-year-old patient is completely demented and has serious heart difficulties), are all cabined to a very circumscribed set of conditions—gravely ill people,

<sup>227</sup> See Dresser & Robertson, *supra* note 208, at 237; Linda Ganzini et al., *Physicians' Experiences with the Oregon Death with Dignity Act*, 342 NEW ENG. J. MED. 557, 563 (2000).

<sup>228</sup> One inference from this is mere existence of the opportunity to end their lives allows them to relax. See BARRY ROSENFELD, *ASSISTED SUICIDE AND THE RIGHT TO DIE: THE INTERFACE OF SOCIAL SCIENCE, PUBLIC POLICY, AND MEDICAL ETHICS* 152–53 (2004).

generally in hospitals, dependent on machines for survival.<sup>229</sup> In contrast, the environment in which PAS for dementia could be carried out is vast.<sup>230</sup>

Some scholars have suggested that advanced directives could be used as a heuristic device (a “tool”) rather than a mandatory device.<sup>231</sup> Used in conjunction with consultation with family and friends, attempted discussion with “the patient,” and input by physician and caregiver, the decision whether to end the person’s life would be made.<sup>232</sup> While this may sound good, if PAS is legal and advanced directives for dementia are the norm, this seemingly rational and philosophically supportable<sup>233</sup> approach generally will be meaningless. For many, there will be no one with whom to consult,

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<sup>229</sup> Persons currently have at least a common law, and perhaps even a constitutional, right to refuse otherwise lifesaving medical treatment. See *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 269–74 (1990); *In re Conroy*, 486 A.2d 1209 (N.J. 1985). One has no comparable right to assistance in dying other than the removal of life-maintaining medical equipment. See *Washington v. Glucksberg*, 521 U.S. 702 (1997). Nonetheless, the right to refuse lifesaving treatment is very significant given that currently eighty percent of people die in hospitals or nursing homes. *Cruzan*, 497 U.S. at 302. About seventy percent of those die as the result of some treatment decision, such as withdrawing support and not providing treatment. George P. Smith II, *Restructuring the Principle of Medical Futility*, 11 J. PALLIATIVE CARE 9, 9 (1995); Marcia Angell, *Helping Desperately Ill People to Die*, in REGULATING HOW WE DIE: THE ETHICAL, MEDICAL, AND LEGAL ISSUES SURROUNDING PHYSICIAN-ASSISTED SUICIDE, *supra* note 11, at 3, 12. A somewhat different estimate (though limited to hospitals) shows that fifty percent of deaths in hospitals from nonemergency cases result from withdrawing lifesaving treatment. Robert T. Hall, *Final Act: Sorting Out the Ethics of Physician-Assisted Suicide*, 54 HUMANIST 10, 10 (1994).

<sup>230</sup> Some have suggested that a living will, which requests cessation of all artificial (or spoon) feeding and hydration if the individual’s dementia reaches the point that the person no longer recalls how to eat or swallow, would be appropriate. See STANLEY A. TERMAN, *THE BEST WAY TO SAY GOODBYE: A LEGAL PEACEFUL CHOICE AT THE END OF LIFE* 201–06 (2007). If this is the limit of using living wills in conjunction with dementia, I would not be extremely concerned. The required status of not recalling how to eat, drink, or swallow generally correlates with end-stage dementia and provides a fairly circumscribed, somewhat objective standard for implementation of the living will. If, however, refusal of lifesaving treatment were tied to some level of cognitive deterioration (e.g., cannot recognize immediate family), then I would strongly object. Even limiting PAS through living wills to cases where the person no longer recalls how to swallow, however, will still leave the serious problem of total interpretative discretion will be the same.

<sup>231</sup> See Widdershoven & Berghmans, *supra* note 126, at 180, 184, 190.

<sup>232</sup> *Id.* at 182–85. But cf. Dresser & Robertson, *supra* note 208, at 239–40 (discussing advance directives and withdrawal of treatment for two conscious, but incompetent, dementia patients and questioning whether such withdrawal “actually serves the incompetent patient’s existing interests”).

<sup>233</sup> See Widdershoven & Berghmans, *supra* note 126, at 188–90.

no one to watch over the person. For the demented, whether the more affluent in private care facilities or the poor in geriatric wards in state mental hospitals, a large percentage have no one really involved in their lives, notwithstanding some infrequent visits.<sup>234</sup> So what will happen? For those without anyone, total interpretive discretion, based in part on subjective feelings and relevant costs, will determine whether the person will live or die—a bit like thumbs up or down in the old Roman Coliseum. And, perversely, the very “malignancy” of the institutional treatment may cause the demented person to appear less worthy of life.

#### IV

#### CONCLUDING THOUGHTS

In previous work, I have argued that suicide and assisted suicide in the context of the terminally ill is not immoral.<sup>235</sup> I feel basically the same about dementia. My concerns go to different matters, matters as tightly woven together as a good rug: our serious societal misconceptions about dementia and the demented and the malignant interrelationship between our misconceived “labels/positioning” and the functioning of the demented in response.

As a result, I am going to take a bold rhetorical stance. “Pollyanna” is a label intended to totally discredit any position that is seen as too positive, too dependent on believing in the positive possibilities of human nature. In this rhetorical move, too positive or too believing is equated with nonpragmatic, nonrealistic. But I believe that well-considered Pollyannaism<sup>236</sup> is pragmatic and, from our lived experience, the most promising stance. We, as a society, should never permit PAS for dementia. Instead, we should (1) alleviate fear—dementia is not a phrase to incite terror; it is the result of a disease like others, and one needs to understand what really happens to those who suffer from it. We should (2) educate—help our society realize that the demented can understand and communicate in their own way and that these people are not empty

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<sup>234</sup> See MARKUT & CRANE, *supra* note 18, at 125 (discussing the range of reasons people do not visit dementia sufferers in institutions).

<sup>235</sup> See MITCHELL, *supra* note 5, at 129.

<sup>236</sup> A term derived from “[t]he name of the heroine of stories written by Eleanor Hodgman Porter (1868–1920), American children’s author, used with allusion to her skill at the “glad game” of finding cause for happiness in the most disastrous situations; one who is unduly optimistic or achieve happiness through self-delusion.” 12 THE OXFORD ENGLISH DICTIONARY 43 (Clarendon Press 2d ed. 1989).

shells or cabbages. And we should (3) spend—invest a fraction of what we currently spend on sports stadiums on research for treatment and (hopefully) cures for Alzheimer’s and other forms of dementia. This is a call to recognize our shared humanity, to kneel down in the garden with my friend’s demented mother, and share the peace of the cool, rich soil.

